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DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 1984

HEARINGS

BEFORE A

SUBCOMMITTEE OF THE

COMMITTEE ON APPROPRIATIONS

UNITED STATES SENATE

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Nondepartmental Witnesses

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DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 1984

WEDNESDAY, APRIL 27, 1983

U.S. Senate,
Subcommittee of the Committee on Appropriations,
Washington, D.C.

The subcommittee met at 8:30 a.m., in room SD–116, Dirksen Senate Office Building, Hon. Lowell P. Weicker, Jr. (chairman) presiding.

Present: Senators Weicker and Proxmire.

NONDEPARTMENTAL WITNESSES

OPENING STATEMENT

Senator Weicker. Good morning, the subcommittee will come to order. Today we begin our public witness hearings on the fiscal year 1984 budgets for the Departments of Labor, Health and Human Services, Education and related agencies.

Due to the large number of witnesses testifying, we're going to use a system of lights to insure we don't get too far behind schedule. The green light will come on to signal the beginning of each witness' 4-minute presentation. When the yellow light appears, you'll have 1 minute to wrap up the statement. The red light means time's up.

I don't like using this system, but we literally have hundreds of people here during the course of the next several days and I hope you'll bear with us.

We will first hear testimony on the proposed budget for the fund for the improvement of postsecondary education.

Two former Members of Congress—and I might add, two very good friends of mine and two gentlemen who brought their great abilities to the Government and are still exercising these abilities in a variety of ways—Jim Symington and Jack Buchanan. Gentlemen, why don't you come up and the floor is yours. The same rules apply for them. [Laughter.]

STATEMENT OF HON. JOHN H. BUCHANAN, JR., CHAIRMAN, NATIONAL BOARD OF THE FUND FOR THE IMPROVEMENT OF POSTSECONDARY EDUCATION

Mr. BUCHANAN. Mr. Chairman, my name is John Buchanan and I'm pleased to have the opportunity to testify as present chairman of the National Board of the Fund for the Improvement of Postsecondary Education.

I'm especially grateful, Mr. Chairman, because we're such a tiny item in the budget that we could get lost in the decimal points. So regardless of the level of funding, when we're talking about $6 to $12 million, that's a tiny item in the Federal budget.

But if there's value in exellence, I think there's value in FIPSE and its work. It is my privilege to have served for some time as the ranking Republican on the Postsecondary Education Subcommittee in the House and to observe from that posture the work of FIPSE, and now as a member of its Board I can report that FIPSE has well fulfilled its congressional mandate to improve postsecondary educational opportunities by encouraging reform and innovation across a wide range of areas.

I think all of us on the present Board have a sense of appreciation for what Jim Symington and others have done, for the leadership of people like Sven Groennings, our executive director and his predecessors; for the work of the staff and those who've served on the Board through the years.

We played a role in the 1970's that I think was significant as we reached out at the Federal and other levels of government to attack basic social inequities in our society and to try to find ways and means through higher education to increase access to adults and minorities and women and workers, the handicapped and the elderly, and many of our projects through the years and this continues to be the case, have zeroed in on how to improve the quality of education and access in education toward serving the ends of social justice and of equity.

But more recently, we have also turned to a second major area, and we remain on the cutting edge of innovation, a major area in our national agenda now; that is, improving our Nation's economy and productive capacity and human confidence.

Postsecondary education has a role, and a significant role, to play in these efforts, and we are working to develop and learn math and quantitative skills to promote scientific and technological literacy, to use increasingly affordable and available electronic technologies, to train scientists and engineers, to help improve secondary education, to create links with employers to help displaced workers, and to train individuals for new careers.

This year 2,300 individuals have brought their ideas to FIPSE on these subjects. Now we've been able to fund only 3 percent of those new proposals at our current budget level.

Of the 23 applications we've had this year—and those applications are increasing year by year—some 500 dealt with math and science skills and many more dealt with related things.

We ran two cuts in our competition; the first reduced the applications from 2,300 to 330, and these were heavily weighted in these areas of national concern at this moment.

Mr. Chairman, we feel that we have a role to play that can be significant in addressing such problems—we have proposals for retired scientists as teachers and many related items. We are excited about what is happening now; we're also deeply proud of FIPSE's record of achievement.

We have to agree with Secretary Bell in his budget proposal: the program has been extremely successful over the past 10 years and a primary reason for that sits beside me.

I think it's appropriate that the chairman of the National Board for 5 years of the 10 years of FIPSE's life should testify now.

PREPARED STATEMENT

Senator WEICKER. Thank you. We will insert your statement in the record.

[The statement follows:]

STATEMENT OF JOHN H. BUCHANAN, JR.

My name is John Buchanan. I appreciate the opportunity to talk with you about the Fund for the Improvement of Postsecondary Education (FIPSE) in my capacity as chairman of its National Board. This is a 15 member Board, appointed by the Secretary of Education to advise the Secretary and the Director of FIPSE about policy, priorities, and funding decisions.

FIPSE is a small discretionary grants program for institutions of postsecondary education created by the Education Amendments of 1972. It was mandated to "improve postsecondary educational opportunities" by encouraging reform and innovation across a wide range of areas.

I was on the House subcommittee which developed the initial FIPSE authorization. Recently I have been able, as a member of the Board, to look back in on what we created. If the congress had been as insightful in all of our legislation as we were in this small authorization, the educational system in this country would be in considerably better shape than it is in currently. I am not saying that we were solely responsible for the remarkable success FIPSE has since achieved. Credit for that must go principally to dedicated and talented directors, a staff of the most intelligent and hard-working government employees to be found in Washington, supportive leadership at both the Department of Health, Education, and Welfare and the Department of Education, and a number of committed professionals and concerned citizens who have served on the FIPSE National Board. Yet the basic insight of the Congress in this case was to write legislation with enough flexibility that capable and imaginative people have discretion to implement the statute in a way that achieves real results.

National Impact through Local Problem-Solving

Since I joined the FIPSE Board in 1982, I have come to understand what this discretion can mean on the leading edge of improvement and change. One way to understand this is to look at the major developments within postsecondary education during the past ten years. Through the 1970s, the Federal government and the entire country continued to work on the persistent and pressing problems caused by some basic social inequities. Within higher education that meant a variety of efforts to increase access to colleges and universities: for adults, minorities, women, workers, the handicapped, and the elderly.

The Federal government, through student financial aid, and the states, by providing facilities and resources, were major partners in this effort. But these major governmental initiatives did not necessarily improve the quality of education. Within this context, FIPSE assumed a responsibility to support improvements in the quality of education for these many new learners, including instruction in basic writing and math skills, assistance to faculty demonstrating more effective teaching methods, closer connections between work and education, and many other types of projects. Importantly, it funded projects which promised to make a difference over the long haul--both in the lives of students and in the development of the institution.

The staff and an outside panel of educational leaders have put together a book A Decade of Learning, about patterns of improvements over the past decade. This book, reminds us how powerfully the cause of social justice and access influenced our institutions of higher education, and served as a profound stimulus to more effective learning. With such a large concern, more accurately viewed as a collection of related sub-problems, there is not one best approach or solution, particularly in a country as large and as diverse as this one. For example, the national crisis in writing is actually the sum of the 1000 or more individual campuses where 200 entering freshmen can't construct a coherent paragraph. FIPSE has been able to support one or several of those institutions to develop a program on its campus to help its 200 students write better. As other institutions learn about successful improvements on one campus it influences their own approaches and soon good ideas have begun to spread. In a number of areas, FIPSE has seen that happen.

The Emerging Agenda

But I think that I joined the Board just in time to see the true genius of this open and flexible approach to grant-making. These large questions of equity, social justice and access are a long way from being completely solved (although I think we've made substantial progress), and FIPSE still receives proposals focusing on these concerns.

In my judgment, however, another major national agenda--improving our nation's economy, productive capacity, and human competence-- is also now requiring major attention from us all. As you know even better than I, making headway on this set of issues will need all of the best ideas and efforts from many different kinds of institutions. Certainly, the postsecondary educational enterprise has a significant role to play in these efforts. Institutions of postsecondary education must develop in learners math and quantitative skills, promote scientific and technological literacy, use the increasingly affordable and available electronic technologies, train scientists and engineers, help to improve secondary education, create links with employers to help displaced workers, and train individuals for new careers. Many of us are just beginning to understand the depth and magnitude of these problems. What is being done about these problems, who is trying to solve them? The answer is that hundreds of educators are working on solutions to these problems. For assistance, they have taken their ideas to solve these problems to a program established to help solve all kinds of educational problems at the postsecondary level. If in fact, this years 2300 individuals have brought their ideas to FIPSE. Consequently, and this is perhaps the most important point about FIPSE I want to make to you--FIPSE has been deluged with proposals addressing precisely these problems for a couple of years.

I just came from a Board meeting where we were going over this year's portfolio. Let me give you a few numbers. First, overall applications are up: from 1750 two years ago, to 2250 last year and 2300 this year-- an alltime high. My hunch is that this was caused by two things:

cutbacks in some other government programs, e.g. the National Science Foundation, and the attractiveness of an open and flexible program in a time of shifting agendas and change.

Second, FIPSE already has in front of it proposals addressing many of the major educational issues that Congress has been wrestling with in the new Jobs Training Partnership Act and the still being developed Emergency Math and Science bill. Out of those 2300 applications:

500 dealt with math and science skills
340 dealt with skills needed by employers or dislocated workers
220 dealt with teacher education or high school college cooperation
835 dealt with educational uses of electronic technology.

To deal with such large numbers, FIPSE conducts a two stage competition. The best 330 of the 2300 applicants are invited to expand their 5-page preliminary proposals into full applications. FIPSE is reviewing these applications right now and the Board will consider them at their June meeting. In these same categories the numbers of full applications are:

80 in math and science
50 in skills needed by employers and retraining dislocated workers
60 in teacher education and high school college cooperation
70 in educational uses of electronic technology.

There is some overlap among these categories, and there are, as usual, a number of other kinds of activities represented also, but I have been impressed that FIPSE is not only understanding some of our emerging major problems before any of the rest of us, but that it is also helping to implement creative solutions to those problems in a time frame considerably shorter than is possible through most of our government mechanisms. Yet their current budget will allow them to fund only one-fourth of those applications currently in front of them, or only 3% of the first stage applicants.

As an example, I would like to focus on one particular problem for just a moment. Fifty percent of our nation's teachers of mathematics have not completed sufficient mathematics courses themselves to be certified to teach mathematics to our children. Only 35 percent of our high school seniors have completed sufficient mathematics courses to preclude their having to take remedial math in college and there has been a 70 percent incease in remedial math services in our nations colleges and universities. What do these statistics mean? They mean the teachers who are teaching mathematics to your children and your grandchildren do not themselves know enough math to teach them properly. It means that even for those teachers who are qualified to teach math, there are very few students electing to take their courses. When those high school students attend a college or university, if they get in, they may not be able to pursue the careers of their choice. And it also means that colleges and universities are expending precious resources in order to bring these students, your children and your grandchildren, up to par. Note that these problems do not exclusively affect the poor or women or minorities, although they do suffer disproportionately. These problems affect everyone. They affect our economy, and they ultimately affect our security. Currently FIPSE has proposals to address these problems: retired scientists as teachers, special workshops for teachers, colleges working with high schools, better math skills in teacher education, and science literacy for all teachers.

This has been for me a fine education in the possiblities in a broadly written piece of legislation when coupled with implementation by highly competent public servants. I've been honored to serve this organization and privleged to share with you some of the excitement that comes from working with an organization that has a practical, let's-solve-it approach to real problems. The fact that they are real local problems, I think , accounts for the extremely high rate of continuation of project activities by the host institution after a grant ends. And the large number of other campuses influenced (without additional federal money) by FIPSE projects testifies to the fact that widely-felt problems are being addressed in individual proposals. FIPSE has even come up with its own jargon (though in common sense language) for this approach. It refers to itself as field-responsive and to proposals as being locally-initiated.

There is more than excitement about new and important ideas at FIPSE. There is also a solid record of achievement. The other members of the Board and I agree with Secretary Bell's statement in his budget message: "The program has been extremely successful over the past ten years."

It is appropriate at this time, I believe, to recognize Jim Symington, my predecessor as chairman of the National Board of FIPSE, to tell you some particular results of a major evaluation conducted of FIPSE when it was part of HEW and he was its Board chair.

STATEMENT OF HON. JAMES W. SYMINGTON, FORMER CHAIRMAN, NATIONAL BOARD OF THE FUND FOR THE IMPROVEMENT OF POSTSECONDARY EDUCATION

Mr. SYMINGTON. Mr. Chairman, good morning.

Senator WEICKER. Good morning, Jim.

Mr. SYMINGTON. My wife asked me this morning whether I would be asking for justice or mercy. [Laughter.]

Senator WEICKER. It depends whether you're going to speak your testimony or sing it. [Laughter.]

Mr. SYMINGTON. Well, I do have a prepared statement which I'll request, as John does his own, that it be incorporated into the records of the committee.

Just before I finished my coffee, I noticed something in this morning's paper—a panel of the National Commission on Educational Excellence had said this:

> If an unfriendly foreign power had attempted to impose upon America the mediocre education performance that exists today, we might well have viewed it as an act of war.

That's not too bad a point of departure for a couple of minutes of discussion here, because we are engaged in the moral equivalent of war, the effort to educate our citizenry at least to be able to take on, not the world but the world's problems and our problems here at home.

One of the first experiences I had as chairman was to visit St. Edwards College down in Texas and they had a program called CAMP—it's a FIPSE program, the college assistance to migrants program.

They went into the fields virtually and identified youngsters who were working for their families and probably would be doing it into their later years, picking cotton. And these were young men and women, and I saw the graduates of that program standing up in the auditorium and giving their expression of their gratitude for it, but more specifically, for the country that made it possible.

And they spoke as well as anybody you ever heard in the Ivy or any other league. They had it in them to do it, but they would have never been identified in the normal course of things, the rush of events, the great categorical programs that we have: the trench warfare that we're constantly engaged in, if this is a war.

I think of FIPSE as being something like the Marines: they can inch on landings, finding out new ways to circumvent problems, both of quality and of access.

They're getting libraries involved, museums: I mean there's no enterprise or institution in this country that shouldn't be searched out for what contribution it can make to the educational process, especially for people who've missed it on the first go and who may need to upgrade their skills in a changing economy structurally and every other way. And without FIPSE these new things aren't happening.

With it they happen, and something like 80 percent of these experimental programs are replicated in the institutions or the enterprises that take them on in the first place—a tremendous increase over and above the average.

Turning to page 5 or so of my prepared text, there is lasting change in institutions: Over 80 percent of the fund's grants were seed grants. And I think I am correct in saying that about 70 percent of them have been replicated, as against usually 5 to 15 percent, all of which is contained in this NTS research evaluation—I think you have a copy of this—HEW requested an independent evaluation of the program.

Think of 2,300 applications and only 70 of them ultimately honored. Think of the screening process that results in that. And imagine cutting the budget, as they appear to want to do, from $14 million and some to $6 million, which wouldn't even quite allow you to continue the things you've already started.

Those are the ones that are already in training—the other $9 or $10 million would be to reach out again, looking for the new answers.

And I think in this day and age we need to keep that kind of momentum for new answers in a changing society, in a rapidly changing world, going.

That's why we hope you'll support the budget, as we see it, and the program in general.

Thank you, Senator.

Senator WEICKER. The budget request is what? The administration request is what?

Mr. SYMINGTON. $6 million, I beg your pardon, $6 million is the administration request, and I believe that $6.7 million is already committed to fiscal year 1983 continuation.

You know, these often run 2 or 3 years, to test out an idea.

So you're killing the heart of the program by cutting it that way to that extent. You might as well just fold the remaining $6 million into some ongoing category.

Senator WEICKER. $11 million was the 1983 request, right?

Mr. SYMINGTON. Yes.

Senator WEICKER. Well, you may be getting help from strange quarters. That report of the administration seems to me to certainly strike from your hands——

Mr. SYMINGTON. Yes.

Senator WEICKER. I heard that very briefly on the radio today, and I heard some superintendent of schools indicate he thought that was merely an argument for tuition tax credits.

Mr. SYMINGTON. Right.

Senator WEICKER. Whereupon the administration vehemently denied that, whereupon I heard the President making a statement that indeed this calls for tuition tax credits and vouchers and prayer in school, et cetera.

But in any event, it would seem to me certainly that it would be very difficult for the administration to have a report like that in their hands and then request the reduced money—I don't know——

Mr. SYMINGTON. I think so.

Mr. BUCHANAN. Mr. Chairman, I think it is possible there's an element of misunderstanding. The administration has come forward with a proposal for 50 percent match in FIPSE in the future, and it may be that they thought if you get 50 percent from other sources and have a $6 million program, you continue at essentially the same level. We——

Senator WEICKER. Let me tell you something, John. I've gone through this business now on the 1983 budget projections by the administration where they counted on *x* number of dollars coming from the private sector or the recapture of *x* number of dollars on loans, or that such and such is going to happen to other projects that are out there, and unfortunately, none of these projections have come true.

I realize I'm looked upon by some as Communistic in my thinking, but that's only on the social side. When it comes to fiscal practice, I think you believe just as I do, that you don't go ahead and count these things until you have them.

Mr. BUCHANAN. Absolutely.

Senator WEICKER. And that's good conservative fiscal practice, which is what I believe in, and if it's $11 million, thank you, but if we find through this year's experience that people come forth with the necessary money, maybe I'll be willing to go ahead and chance it.

Mr. BUCHANAN. Well, truth to tell, Mr. Chairman, I was about to say that we already have a 40-percent match at present this year. Forty percent of the funds come from somewhere else, and as Jim has said, there is an 80-percent retention rate in the institution, and a 70-percent spin-off rate. We're spinning them off year by year, so we probably in the 4 months are doing better than a mechanical 50 percent match and we do have a 40-percent-on-average match, which means that the cut would be a cut in program and impact.

If we got up to 50, we'd just be 10 percent better in terms of outside help by any measure. But I think this could have been a factor in the $6 million request.

Senator WEICKER. Gentlemen, thank you very much.

Mr. BUCHANAN. Thank you.

Senator WEICKER. It's good seeing you. I wish you were a part of us rather than the other side.

Mr. SYMINGTON. I tried. [Laughter.]

Senator WEICKER. So did John. [Laughter.]

Mr. BUCHANAN. Both involuntarily resigned. [Laughter.]

PREPARED STATEMENT

Senator WEICKER. Have a nice day. Your statement will be included in the record.

[The statement follows:]

STATEMENT OF JAMES W. SYMINGTON

My own involvement with the Fund for the Improvement of Postsecondary Education began in 1977, and lasted through 1981.

As Chair of the FIPSE National Board, I had the role of advising the Director and staff to support and encourage new and even risky initiatives while also using public dollars in wise and cost-effective ways.

The assignment is voluntary (unpaid). I have been hooked by the issues and their increasing importance inspired by the constructive efforts of imaginative entreprenuers and committed educational leaders.

In addition, my service has been a pleasure because of the high professionalism of the Director and staff and the thoughtful commitment of the members of the Board.

I want to speak today of the Fund's background and record. The Fund was established by the Higher Education Amendments of 1972, as a response to the concerns of several major commissions and studies. Current Fund programs focus on problems that are still unsolved, as well as on new agendas. Because of the Fund's unique operating style, it has been able to hammer away at the traditional problems of improving writing, math and thinking skills while at the same time responding to these and other problems in the context of the times. So that for instance, I happen to know that right now they are reviewing a group of proposals directed at upgrading the skills of unemployed workers.

The Fund has enjoyed relative independence in developing its programs and procedures. The Fund's separate status and National Board have been established by statute. It operates in ways similar to the National Endowment for the Arts and Humanities and the National Science Foundation.

The Fund was begun at the same time as a major expansion of student financial aid dollars, which gave impetus to much increased access to higher education -- clearly the most dramatic development of recent years.

The Fund's authorizing legislation was, however, very different from the financial aid legislation, and of course the Fund was not intended to be a large entitlement program. The Fund instead was authorized to "encourage reform, innovation, and improvement" in eight broad areas, reaching beyond traditional higher education to "postsecondary education," and encompassing, for example, career and professional training, the technology of communications, and graduate education.

At the same time, the National Institute of Education (NIE) was established. NIE focused on basic research, mainly in the pre-college years. In contrast, the Fund was led by its first Director and Board of Advisors to support action projects mainly beyond high school. The underlying purpose of both agencies was to improve the quality of education. Both the Fund and NIE developed competitive grants programs, rather than making awards on a predetermined "categorical" basis. Both new agencies gained and profitted from considerable autonomy from HEW's existing Office of Education.

General Approach

The Fund defines postsecondary education broadly, to include all agencies and institutions offering education after high school, such as colleges and universities (public and private, two or four year), technical and business schools, testing agencies, professional associations, employers and unions, state and local education agencies, student organizations, cultural institutions, and community groups. The Fund supports new as well as established organizations.

The Fund has mainly worked through modest "seed" grants serving as incentives for improvement. Fund grant competitions share certain characteristics:

-- They focus on widely felt problems in postsecondary education, rather than on special interest groups or prescribed solutions.

-- Fund programs are responsive to local initiative, leaving to the applicants the task of identifying specific local problems and proposing solutions.

- -- Fund programs are comprehensive with respect to the variety of problems addressed and the range of institutions and learners served.
- -- Fund projects are action-oriented, usually involving direct implementation of new ideas or approaches rather than basic research.
- -- The Fund is risk-taking in its willingness to support new and unproven ideas we well as proven ones.

Priority Setting

The most unusual feature of the Fund among education programs is its broad mandate, allowing a unique capacity to respond to needs and problems as they arise. The Fund views postsecondary education as a system involving related concerns, and within that system the Fund's mission of improvement requires strategic choices to establish and pursue priorities. The whole portfolio of Fund projects thus represents an agenda for improvement which could not be derived from more categorical approaches. The Fund becomes aware of postsecondary problems through wide consultation, beginning with its National Board of Advisors and including many groups and individuals in the field. The Comprehensive Program establishes priority concerns through published guidelines and through the responses of large numbers of applicants. From time to time the Fund also sponsors targetted competitions to focus resources on a more particular problem. However, even in such competitions problems are not narrowly defined, applicant elgibility is not limited, and the Fund depends on the field for creative solutions.

Other Leadership Roles

A major development is shared support for grants programs with other agencies, including those outside the Department of Education. A program addressing youth unemployment worked with funds from the Department of Labor. The Mina Shaughnessy Scholars Program is partially funded by the Carnegie Corporation; this is the Department's first cooperative effort with a private foundation.

Dissemination of Fund-supported ideas has become a major priority, with the purposes of sharing invaluable information and encouraging the adaptation of proven programs. The Fund has sponsored national conferences on work and learning, youth employment, writing improvement, and liberal education. Information about all current projects was provided through Resources for Change, an annual publication, and through other, more occasional reports which also are vehicles of dissemination.

The Fund is increasingly looked on by policymakers as an appropriate agency to take on new or expanded responsibilities. After ten years of operation, the Fund staff, projects and Board represent a considerable resource of usable knowledge for educational improvement.

Evaluation of the Fund

During my tenure as Chair, HEW supported a major independent evaluation of the Fund. It was carried out by the NTS Research Corporation. The results are now in, and they are surprising and heartening for a federal education program. (I have brought copies of the FINAL REPORT for your attention.) Some of the key findings:

1. The Fund has succeeded in creating lasting change in institutions: Over 80% of the Fund's grants under study were "seed grants" -- designed to create an improvement or program that would live after the grant ended. The research team devoted special attention to this issue of continuation; a RAND study of four large Federal seed money educational programs had found the rates of institutionalization to be very low (5-15%). By contrast, seventy percent of the Fund's seed money projects met the criteria of institutionalization, a success rate several times higher than expected. Moreover, half had expanded their services or enrollments since the end of their grants. And this continued improvement almost never used Federal money.
2. The Fund has succeeded in stimulating improvements elsewhere: NTS found that the projects each typically had received hundreds of

requests for information. Their studies of other institutions confirm that a substantial amount of adaptation of project results is taking place in other institutions, without further Federal support. This widespread influence was also well-known in the field. More than half the postsecondary educators surveyed who were aware of a Fund project somewhere in the country felt that the project had positively influenced their own institution.

3. The Fund has succeeded in attracting proposals from an unprecedented range of applicants. The Fund's procedures were so known and accessible that 35% of the winners of grants were people who had never before applied to the Federal government (let alone the Fund) for support. And the proposals (typically 20-35 for every available grant) come from every state and type of organization. The evaluators concluded "that the Fund has been successful in communicating its mission to a broadly diverse field of postsecondary educational institutions and organizations... the Fund receives applications from a broad range of institutions and organizations that are representationally distributed across the country."

4. The Fund has succeded in supporting projects that fulfill the Congressional mandate. The evaluation reports, "not only have all the projects supported by the Fund addressed at least one of the original eight purposes, but a large majority of projects have addressed more than one purpose. In fact, 96 percent of the projects simultaneously addressed at least five of the eight purposes."

A lot of the projects supported by the Fund have proven to be of great continuing interest to educators at all levels: new forms of education for adults who can only study part-time, improved methods of teaching essential skills like writing and math, and better information for student choice are only some of the examples.

But with all that has been accomplished, the Fund's budget has had problems. There was modest growth over the first eight years, to a level of $13.5 million; still a very small amount. Since 1981 the budget has declined to the current $11.7, and currently the Administration proposes a reduction to $6 million. You heard John Buchanan mention the large numbers of proposals in emerging areas such as educational uses of technology and science and engineering, which are inherently more expensive than some matters supported in earlier years.

In my personal view it would be "penny wise/pound foolish" to cut the FIPSE budget at a time when investment in improving education is more needed than ever.

STATEMENT OF SANDRA DUCKWORTH, SUPERVISOR, FAIRFAX COUNTY, VA., ON BEHALF OF THE NATIONAL ASSOCIATION OF COUNTIES

Senator WEICKER. We now have Sandy—is it Mr. or Mrs. Sandy Duckworth?

Miss DUCKWORTH. Miss.

Senator WEICKER. Fine. I beg your pardon. Miss Duckworth, member of the board of supervisors of Fairfax County, National Association of Counties.

Miss Duckworth, if you'll sit down and make yourself comfortable; it's a pleasure to have you before the committee.

Miss DUCKWORTH. Thank you very much; it's a pleasure to be here. Sandra will be fine, actually. [Laughter.]

Senator WEICKER. Why, I have a lot of friends, male, that are Sandys also. So that's why I was a little——

Miss DUCKWORTH. I know.

Senator WEICKER. But I'm delighted that it's you that's on the other side. You may proceed.

Miss DUCKWORTH. Mr. Chairman, it's a pleasure to be here. I am a member of the Fairfax County Board of Supervisors in Virginia, and I currently serve on the Governor's Commission on Block Grants in the Commonwealth, and I am a member of the National Association of Counties' Human Services Steering Committee and I am here today on behalf of the approximately 3,000 counties that comprise the membership of NACO. These counties represent 90 percent of our Nation's population and we must, as you know, provide many services which range from income maintenance to health care in the human needs area.

And Mr. Chairman, your long day has just begun and I know that you and your subcommittee have heard or will be hearing from a seemingly endless array of individuals, groups, lobbyists, and so forth, all bringing the same message: that more resources are necessary. And as a policymaker who has just completed in microcosm at the local level what you face at the national level, I can identify with you and your awesome task.

While the Fairfax County budget is approximately $1 billion, the responsibility is no less compelling and the need is painfully evident, as is yours.

Thus, I appear before you as one who struggles with similar problems speaking on behalf of the thousands of other local officials to ask that in our efforts to arrive at your decisions on the fiscal year 1984 appropriations, you not further reduce our ability to meet the human needs of our least fortunate citizens.

The membership of the National Association of Counties continues to endorse the goal of the balanced budget; however, we do not feel that a balanced budget should be achieved at the expense of further reduction in the funding for the domestic programs.

It is fundamentally wrong for a country to increase defense spending and at the same time cut the heart from those programs which provide basic life-sustaining services to the most needy in our society.

Senator, you must provide for the butter as well as for the guns. Counties are facing tremendous financial burdens as they strive to support the growing numbers of people who are ineligible for Federal AFDC and food stamps or unemployment insurance and further reductions in revenues would seriously and negatively impact on the ability of our counties to provide basic and vital services to our citizens.

The 1983 Supplemental Appropriations bill does relieve some of our concerns for the short run; however, we would oppose cutting fiscal year 1984 moneys to accommodate the fiscal year 1983 supplemental funds recently authorized as a part of the jobs bill.

We do continue to support Federal funding for the national job training system; we feel that the House-passed first budget resolution meets this goal. However, language should be added to create a 90-percent substate hold harmless.

In addition, we support funding youth employment under title II–B at $825 and $93 million for the dislocated workers program.

County health care facilities and resources are an essential link in our Nation's effort to insure access to quality health care for all Americans. The proposed fiscal year 1984 budget cuts in health care, including medicare and medicaid, in combination with already achieved cuts would undermine the financial viability of workable Government facilities.

NACO urges the subcommittee to propose funding for the health care grants at their authorized levels. Forty-seven States have reported cutbacks in the title V maternal and health care block grant program.

I am confident that you and your committee do care about a child's health.

NACO recommends that Congress fully fund the programs authorized by the Older Americans Act. The proposed $32 million reduction in nutrition programs would curtail if not terminate many meals served to the elderly under county programs. And who among us wants to see the elderly go hungry?

NACO also opposes any budget reductions in the AFDC program, especially during the current economic situation. NACO supports retaining the WIN funds, since it pays for child care and training programs and is the only program to place welfare recipients into jobs.

NACO has long held the position that full Federal reimbursement must be available for the cost of assisting refugees until they become self-sufficient.

Mr. Chairman, it's been my pleasure to be before you today. You do have a full copy of our testimony with all backup information, and we will be very pleased to answer any questions that you have.

Senator WEICKER. Sandy, thank you very much. I have just one question. All the testimony that we received from administration officials in presentation of their budget indicates that these shortfalls are going to be picked up by local and State governments and the private sector and volunteers.

We've been into this situation for a couple of years and I'd just like to ask if you could briefly indicate as to whether that is or is not taking place.

Miss DUCKWORTH. OK. In the Commonwealth of Virginia, it is not taking place. We are striving to work with the State. The State does continue to do some mandating without funding; there is work with the local businesses and with the private sector and they are doing a share. However, we still have many needy who are not being served.

You don't have those that are actual risks because the Government in one way or another will take care of them, but we have in our jurisdiction realized several millions of dollars of loss in Federal and State funding and anticipate additional such losses.

So it is tremendous and no one group can pick up everything.

PREPARED STATEMENT

Senator WEICKER. Thank you very much for your testimony. I appreciate it.

Miss DUCKWORTH. I appreciate the opportunity to testify. Thank you.

[The statement follows:]

STATEMENT OF SANDY DUCKWORTH

MR. CHAIRMAN, MEMBERS OF THE SUBCOMMITTEE, MY NAME IS SANDY DUCKWORTH. I AM A MEMBER OF THE BOARD OF SUPERVISORS IN FAIRFAX COUNTY, VIRGINIA. I AM ALSO ON THE GOVERNOR'S COMMISSION ON BLOCK GRANTS IN VIRGINIA AND AM A MEMBER OF NACo'S HUMAN SERVICES STEERING COMMITTEE. I AM ACCOMPANIED BY SUSAN WHITE, NACo LEGISLATIVE REPRESENTATIVE.

WE ARE HERE TODAY ON BEHALF OF THE COUNTIES THAT COMPRISE THE MEMBERSHIP OF THE NATIONAL ASSOCIATION OF COUNTIES (NACo). THE MEMBER COUNTIES OF NACo REPRESENT 90 PERCENT OF OUR NATION'S POPULATION AND RANGE FROM SMALL RURAL COUNTIES WITH POPULATIONS OF LESS THAN 5,000 TO DENSELY POPULATED URBAN COUNTIES WITH POPULATIONS OVER 1 MILLION. THESE COUNTIES PROVIDE THEIR CITIZENS WITH A RANGE OF SERVICES FROM INCOME MAINTENANCE TO EMPLOYMENT AND TRAINING, TO HEALTH CARE.

THE MEMBERSHIP OF NACo HAS BEEN CONCERNED FOR SOME TIME ABOUT THE SIZE OF THE FEDERAL DEFICIT, AND WE CONTINUE TO ENDORSE THE GOAL OF A BALANCED BUDGET. HOWEVER, WE DO NOT FEEL THAT THAT SHOULD BE ACHIEVED AT THE EXPENSE OF FURTHER REDUCTIONS IN FUNDING FOR DOMESTIC PROGRAMS IN FISCAL 1984. DURING THE LAST SEVERAL YEARS, COUNTIES HAVE SUSTAINED OVER 20 PERCENT REDUCTION IN FEDERAL FUNDING. THE EFFORTS THAT COUNTY GOVERNMENTS ARE MAKING TO MAINTAIN SERVICE LEVELS DESPITE FUNDING CUT BACKS ARE TREMENDOUS. WHILE THE FULL IMPACT OF ALL THE CUTS HAVE NOT BEEN REALIZED, IT IS NOW CLEAR THAT ALL OF THE "FAT" HAS BEEN ELIMINATED. LAST YEAR'S CUTS FORCED MANY COUNTIES TO REDUCE EMPLOYMENT, CUT BACK ON SOME CRITICAL SERVICES, SUCH AS DAY CARE ASSISTANCE AND POSTPONE INVESTMENT IN INFRASTRUCTURE REPAIRS. MANY COUNTIES HAVE HAD TO RAISE PROPERTY OR SALES TAXES, A POLICY VIEWED UNFAVORABLY BY CITIZENS WHO RECEIVE IN RETURN, A CUTBACK RATHER THAN AN INCREASE IN SERVICES. COUNTIES ARE FACING ADDITIONAL BURDENS AS THEY STRIVE TO SUPPORT THE GROWING NUMBERS OF PEOPLE WHO ARE INELIGIBLE FOR FEDERAL AFDC AND FOOD STAMPS, OR UNEMPLOYMENT INSURANCE. MANY COUNTIES HAVE DIFFICULTY IN MAINTAINING THE FISCAL VIABILITY OF COUNTY HOSPITALS WHICH PROVIDE SERVICES TO

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*THE NATIONAL ASSOCIATION OF COUNTIES IS THE ONLY NATIONAL ORGANIZATION REPRESENTING COUNTY GOVERNMENT IN THE UNITED STATES. THROUGH ITS MEMBERSHIP, URBAN, SUBURBAN, AND RURAL COUNTIES JOIN TOGETHER TO BUILD EFFECTIVE, RESPONSIVE COUNTY GOVERNMENT. THE GOALS OF THE ORGANIZATION ARE TO: IMPROVE COUNTY GOVERNMENT; SERVE AS THE NATIONAL SPOKESMAN FOR COUNTY GOVERNMENT; ACT AS A LIAISON BETWEEN THE NATION'S COUNTIES AND OTHER LEVELS OF GOVERNMENT; ACHIEVE PUBLIC UNDERSTANDING OF THE ROLE OF COUNTIES IN THE FEDERAL SYSTEM.

POOR PEOPLE WHO ARE INELIGIBLE FOR MEDICARE AND MEDICAID, INCLUDING MANY "NEWLY POOR". FURTHER REDUCTIONS IN REVENUES WOULD SERIOUSLY AND NEGATIVELY IMPACT ON THE ABILITY OF COUNTIES TO PROVIDE BASIC AND VITAL SERVICES TO CITIZENS.

OVER 1400 COUNTY OFFICIALS FROM ACROSS THE NATION CAME TO WASHINGTON FOR NACo'S LEGISLATIVE CONFERENCE IN FEBRUARY. THE RECORD-BREAKING ATTENDANCE AT THIS CONFERENCE REFLECTED THE DEPTH OF INTEREST AND CONCERN OF COUNTY OFFICIALS. BROAD SUPPORT WAS GIVEN TO THE OVERALL GOALS OF INCREASING LOCAL AND STATE GOVERNMENT'S RESPONSIBILITY AND AUTHORITY FOR DOMESTIC PROGRAMS. THE CONCERN WAS EXPRESSED, HOWEVER, THAT LOCAL GOVERNMENTS MAY NOT HAVE ADEQUATE FUNDING RESOURCES TO MEET THESE RESPONSIBILITIES.

THIS YEAR, AFTER CONSIDERATION OF THE IMPACT OF LAST YEAR'S BUDGET CUTS AND THE POTENTIAL IMPACT OF ADDITIONAL CUTS, THE BOARD OF DIRECTORS REAFFIRMED ITS CALL FOR A MORATORIUM ON FEDERAL BUDGET REDUCTIONS IN DOMESTIC PROGRAMS AFFECTING LOCAL AND STATE GOVERNMENT. WE RECOGNIZE THAT THESE CONCERNS ARE SHARED BY CONGRESS AND THE MEMBERS OF THIS COMMITTEE.

THE 1983 URGENT SUPPLEMENTAL APPROPRIATIONS BILL (H.R.1718) RELIEVES SOME OF OUR CONCERNS FOR THE SHORT RUN. FUNDING FOR FISCAL YEAR 1984 ALSO NEEDS TO ADDRESS COUNTIES' CONCERNS FOR THE RISING NUMBERS OF NEW POOR, THE UNEMPLOYED WITHOUT HEALTH INSURANCE, AND THE NEEDY WHO HAVE LOST VITAL SERVICES AS A RESULT OF CUTBACKS.

WE WOULD OPPOSE CUTTING FY'84 MONIES TO ACCOMMODATE THE FY'83 SUPPLEMENTAL FUNDS RECENTLY AUTHORIZED AS PART OF THE JOBS BILL; THIS WOULD ENSURE THAT NEXT YEAR WE WILL HAVE THE NECESSARY FUNDS IN PLACE.

EMPLOYMENT AND TRAINING

WE CONTINUE TO SUPPORT THE NEED FOR FEDERAL FUNDING FOR THE NATIONAL JOB TRAINING SYSTEM. WE FEEL THAT THE HOUSE-PASSED FIRST BUDGET RESOLUTION (H.CON.RES.90) MEETS THIS GOAL. WE FULLY SUPPORT FUNDING AT A LEVEL OF $4.7[1] BILLION FOR TITLES II AND III OF THE JOB TRAINING PARTNERSHIP ACT (JTPA) AND URGE YOUR SUBCOMMITTEE TO SUPPORT THIS LEVEL IN YOUR APPROPRIATION FOR FISCAL YEAR 1984. WE ALSO SUPPORT FUNDING FOR JOB CREATION ACTIVITIES SIMILAR TO THAT OF H.R.1036, THE COMMUNITY RENEWAL AND EMPLOYMENT ACT.

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[1] THIS FIGURE DOES NOT INCLUDE FUNDING FOR JOB CORPS AT APPROXIMATELY $.616 BILLION.

WE URGE YOU TO GUARANTEE THAT COUNTIES AND OTHER SUBSTATE LOCALITIES RECEIVE NO LESS THAN $1.9 BILLION AVAILABLE IN FISCAL YEAR 1983 BY PROVIDING A MINIMUM OF $2.5 BILLION IN TITLE II-A; BE PROVIDED SUFFICIENT FUNDS FOR NINE MONTHS FORWARD FUNDING ($3.911B); AND URGE THAT AN ADDITIONAL $1 BILLION BE APPROPRIATED. LANGUAGE SHOULD BE ADDED TO CREATE A 90 PERCENT SUBSTATE HOLD HARMLESS.

IN ADDITION, WE SUPPORT FUNDING YOUTH EMPLOYMENT UNDER TITLE II-B AT $825 MILLION AND $93 MILLION FOR THE DISLOCATED WORKERS PROGRAM.

WE ARE CONCERNED THAT CHANGES IN THE NEW JTPA FORMULA ALLOCATION AND CHANGES IN THE PERCENT OF FUNDS DISTRIBUTED TO SERVICES DELIVERY AREAS, (FROM 86 PERCENT TO 76 PERCENT), WILL REDUCE FUNDS TO LOCAL AREAS BY 10 PERCENT. CHANGES IN THE FORMULA DISTRIBUTION AND A FIVE TO TEN PERCENT INFLATION FACTOR WOULD REDUCE FUNDS TO LOCAL AREAS BY A TOTAL OF 20 PERCENT.

WE ARE ADDITIONALLY CONCERNED WITH AND WILL OPPOSE ANY ATTEMPT THAT WOULD CHANGE THE CURRENT JTPA PROGRAM YEAR--OCTOBER 1, 1983 THROUGH JUNE 30, 1985. AS YOU KNOW, THE ADMINISTRATION IS ON RECORD AS SUPPORTING A CHANGE IN THE PROGRAM YEAR CONCEPT (JANUARY 1 THROUGH DECEMBER 31) AND WILL ONLY PROVIDE $912 MILLION IN FORWARD FUNDING. NACo SUPPORTS THE JTPA PROGRAM YEAR CONCEPT AND BELIEVES THAT NINE MONTHS FUNDING AT $3.911 BILLION IS REQUIRED TO SUFFICIENTLY PLAN AND IMPLEMENT THE NEW JOB TRAINING PROGRAM.

HEALTH CARE

WE ARE ASKING FOR RESTORED FUNDING FOR ALL PROGRAMS TO BE INCLUDED IN THE HEALTH BLOCK GRANTS AND NO FURTHER CUTS IN THE MEDICAID PROGRAMS. WE ARE ALSO REQUESTING THAT HEALTH PLANNING BE FUNDED AT THE PRESENT LEVEL OF $64 MILLION, FOR STATE AND LOCAL PLANNING ACTIVITIES.

COUNTY HEALTH CARE FACILITIES AND RESOURCES ARE AN ESSENTIAL LINK IN OUR NATION'S EFFORT TO ASSURE ACCESS TO QUALITY HEALTH CARE FOR ALL AMERICANS. THE PROPOSED FY 1984 BUDGET CUTS IN HEALTH CARE, INCLUDING MEDICARE AND MEDICAID, IN COMBINATION WITH ALREADY ACHIEVED CUTS, WOULD UNDERMINE THE FINANCIAL VIABILITY OF COUNTY FACILITIES, THEREBY JEOPARDIZING THE CARE OF ALL THEY SERVE.

IN 1980, THE COST TO LOCAL GOVERNMENTS FOR PROVIDING HEALTH CARE SERVICES AMOUNTED TO SOME $13 BILLION. SINCE THAT TIME, HEALTH COSTS HAVE INCREASED AT THE RATE OF 15 PERCENT A YEAR, WHILE

MEDICAID AND OTHER FEDERAL AND STATE HEALTH FUNDING HAS BEEN REDUCED. FEDERAL AND STATE BUDGET CUTS COUPLED WITH A CONTINUED ESCALATION IN COSTS WILL FORCE FURTHER REDUCTIONS IN SERVICES.

NACo IS CONCERNED THAT AN EXTENSION OF A 3 PERCENT FEDERAL MATCHING REDUCTION UNDER MEDICAID WILL PLACE ADDITIONAL BURDENS ON COUNTY GOVERNMENTS. CONTINUATION OF THE WITHDRAWAL OF FEDERAL SUPPORT FOR MEDICAID WILL FORCE STATES TO COME UP WITH A LARGER SHARE, WHICH MANY COUNTIES WILL THEN BE CALLED UPON TO MATCH.* THERE WILL BE FURTHER REDUCTIONS IN SERVICES. IF SERVICES CONTINUE TO BE CUT BACK, THE COST-SHIFTING IMPLICATIONS FOR COUNTIES AND PUBLIC HOSPITALS WILL BE DRASTIC.

NACo URGES THE SUBCOMMITTEE TO PROPOSE FUNDING FOR THE HEALTH BLOCK GRANTS AT THEIR AUTHORIZED LEVELS.** THE NACo BOARD OF DIRECTORS RECENTLY PASSED A RESOLUTION CALLING FOR INCREASED FUNDING FOR THESE PROGRAMS, PARTICULARLY IN LIGHT OF HIGH UNEMPLOYMENT AND RECENT CUTS RESULTING IN HIGHER COSTS TO COUNTIES.

FORTY-SEVEN STATES HAVE REPORTED CUTBACKS IN THE TITLE V MATERNAL AND CHILD HEALTH BLOCK GRANT PROGRAM. MANY COUNTIES HAVE TRIED TO MAKE UP THIS DIFFERENCE BY INCREASING THEIR OWN SHARE, ONLY TO FIND THAT THEY STILL MUST REDUCE ESSENTIAL SERVICES.

PROPOSED CUTS IN PROGRAMS THAT OFFER THE HOPE OF MODEST, SHORT-TERM SAVINGS ARE OF EQUAL CONCERN WHERE HIGHER LONG-TERM COSTS ARE SURE TO RESULT. IN EFFORTS TO SPREAD REDUCED PREVENTION BLOCK GRANT DOLLARS, STATES ARE CUTTING BACK OR ELIMINATING FLUORIDATION, HYPERTENSION, RODENT CONTROL, AND OTHER PREVENTION PROGRAMS. COUNTIES ARE CONCERNED ABOUT THE POTENTIAL LIFE THREATENING IMPLICATIONS OF FURTHER CUTBACKS IN THESE PROGRAMS THAT ARE SO OFTEN TAKEN FOR GRANTED.

OLDER AMERICANS

NACo RECOMMENDS THAT CONGRESS SHOULD FULLY FUND THE PROGRAMS AUTHORIZED BY THE OLDER AMERICANS ACT. THE ADMINISTRATION's OVERALL BUDGET PROPOSAL FOR OLDER AMERICANS REPRESENTS A $56 MILLION REDUCTION IN OLDER AMERICANS ACT PROGRAMS.

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* A SUMMARY OF STATES REQUIRING A COUNTY MEDICAID MATCH AND A DESCRIPTION OF EACH MATCH IS ATTACHED FOR THE RECORD

** MATERNAL AND CHILD HEALTH AT $478.5 MILLION (INCLUDING THE $105 MILLION IN FISCAL 1983 SUPPLEMENTAL APPROPRIATION). PREVENTATIVE HEALTH AT $98 MILLION; ALCOHOL, DRUGE ABUSE AND MENTAL HEALTH AT $462 MILLION.

THE PROPOSED $32 MILLION REDUCTION IN THE NUTRITION PROGRAMS WOULD CURTAIL, IF NOT TERMINATE, MANY MEALS SERVED TO THE ELDERLY UNDER COUNTY PROGRAMS. WE ARE ALSO CONCERNED THAT THE PROPOSAL TO TRANSFER THE USDA FOOD COMMODITIES PROGRAM TO THE ADMINISTRATION ON AGING WOULD RESULT IN A 10 PERCENT LOCAL MATCH REQUIREMENT, AS IS PRESENTLY REQUIRED ON THE TITLE III-C NUTRITION PROGRAMS. THE 10 PERCENT LOCAL MATCH REQUIREMENT WOULD PUT COUNTIES IN THE POSITION OF CUTTING BACK THE NUMBER OF MEALS SERVED.

THE PRESIDENT'S BUDGET WOULD MAINTAIN TITLE III-B SOCIAL SERVICES AT CURRENT FUNDING LEVELS, WHICH AFTER INFLATION IS ABOUT THE SAME LEVEL AS 1973. COUNTIES USE THE VITAL TITLE III-B SOCIAL SERVICES -- HOMEMAKER AND HOME HEALTH CARE, TRANSPORTATION, AND VOLUNTEERS TO DELIVER MEALS -- TO MAINTAIN OLDER PEOPLE AT HOME, RATHER THAN IN MORE EXPENSIVE INSTITUTIONAL SETTINGS.

SOCIAL SERVICES AND INCOME SECURITY

NACo CALLS FOR A MORATORIUM ON ANY FURTHER CUTS IN THE SOCIAL PROGRAMS AFFECTING THE NATION'S POOR. AT THE COUNTY LEVEL, PROGRAM REDUCTIONS THREATEN OUR CAPACITY TO MAINTAIN ESSENTIAL LIFE-SUSTAINING SERVICES. FOR EXAMPLE, AS THE INCIDENCE OF CHILD ABUSE IS INCREASING NATIONWIDE, MANY COUNTIES HAVE HAD TO LAY OFF STAFF, REDUCING OUR ABILITY TO RESPOND ADEQUATELY TO PROTECT CHILDREN AT RISK. WIDESPREAD PROBLEMS OF HOMELESSNESS, HUNGER, AND UNEMPLOYMENT ARE ADDING FURTHER STRAINS.

OF GREATEST IMPORTANCE IS RESTORATION OF THE SOCIAL SERVICE BLOCK GRANT AND COMMUNITY SERVICES BLOCK GRANT FUNDS THAT PROVIDE THE BASE FOR THESE LOCAL SERVICES. WE URGE YOU TO RESTORE THE SOCIAL SERVICES BLOCK GRANT TO $3.1 BILLION LEVEL AUTHORIZED IN THE STATUTE, AND TO RETAIN THE $25 MILLION ADDITIONAL FUNDS FOR THE COMMUNITY SERVICES BLOCK GRANT WHICH CONGRESS JUST ENACTED FOR FY 1983.

NACo ALSO OPPOSES ANY BUDGET REDUCTION IN THE AFDC PROGRAM, ESPECIALLY DURING THE CURRENT ECONOMIC SITUATION.

THE PROBLEM OF LIMITED FEDERAL REIMBURSEMENT FOR WORK PROGRAMS IS EXACERBATED BY A SEPARATE BUDGET PROPOSAL TO ELIMINATE THE $271 MILLION WORK INCENTIVE (WIN) PROGRAM: A PROPOSAL CONGRESS REJECTED LAST YEAR. NACo SUPPORTS RETAINING THE WIN FUNDS, SINCE IT PAYS FOR CHILD CARE AND TRAINING AND IS THE ONLY PROGRAM TO PLACE WELFARE RECIPIENTS INTO JOBS.

FOR REFUGEE AND ENTRANT ASSISTANCE PROGRAMS, NACo OPPOSES THE $270 MILLION STATE PER-CAPITA BLOCK GRANT FOR REFUGEES CATEGORICALLY INELIGIBLE FOR NORMAL CASH AND MEDICAL ASSISTANCE PROGRAMS. NACo HAS LONG HELD THE POSITION THAT FULL FEDERAL REIMBURSEMENT MUST BE AVAILABLE FOR THE COSTS OF ASSISTING REFUGEES UNTIL THEY BECOME SELF-SUFFICIENT. A CAPPED BLOCK GRANT WOULD LIKELY BE INSUFFICIENT, ESPECIALLY IF THERE WAS AN UNEXPECTED IMMIGRATION FLOW, SUCH AS THE CUBAN MARIEL BOATLIFT OF 1980. NACo OPPOSES BLOCK GRANTS FOR FEDERAL ENTITLEMENT ASSISTANCE PROGRAMS THAT WOULD SHIFT A FEDERAL RESPONSIBILITY, SUCH AS THE EFFECTS OF IMMIGRATION, TO COUNTY AND STATE BUDGETS.

ATTACHMENT

The following indicates as of March 10, 1983, which states require a local Medicaid match, and what the local funding formulas are.

The survey was conducted by the National Association of Counties and information was obtained through the State Associations of Counties and the Health Care Financing Administration.

The states of California, Nevada and New Jersey have taken over the full non-federal share in the last few years and the state of Colorado has instituted a local match requirement for the 20 largest counties, since HCFA's last update in 1979. Thirteen states require a local match.

Colorado

20 largest counties pay 2% of state's share for all new ICFS nursing admissions.

Florida

County pays $55 per month for each nursing home resident, 35% of each share for inpatient hospital days over 12 and less than 46, and 100% state share for certain outpatient services.

Iowa

Counties must match federal funds for ICFS/MRs.

Minnesota

Counties pay 10% of states share.

Montana

Counties pay 18% of eligibility, personnel costs.

Nebraska

Counties pay 14% of states share.

New Hampshire

Counties pay approximately 25% of states share.

New York

Counties pay 50% of non-federal share.

North Carolina

Counties pay 50% of non-federal share for all services except ICFS/SNFS for which they pay 35% of non-federal share.

North Dakota

Counties pay 15% of states share except for ICF/MR and two other services.

Pennsylvania

Counties pay 10% of states share for county nursing homes and $3 for invoice administration fee.

South Dakota

$60 per month for each ICF/MC resident and some services provided in crippled children's hospitals.

Wisconsin

. Local contribution of 10-20% for specific services, i.e., mental health.

STATEMENT OF JOHN A. CANFIELD, COMMISSIONER, WEST VIRGINIA DEPARTMENT OF EMPLOYMENT SECURITY AND PRESIDENT-ELECT OF THE INTERSTATE CONFERENCE OF EMPLOYMENT SECURITY AGENCIES, INC.

ACCOMPANIED BY WILLIAM L. HARGROVE, EXECUTIVE VICE PRESIDENT, INTERSTATE CONFERENCE OF EMPLOYMENT SECURITY AGENCIES, INC.

PREPARED STATEMENT

Senator WEICKER. Our next witness is Mr. John Canfield, president-elect of the Interstate Conference of Employment Security Agencies, Inc.

Mr. HARGROVE. I am just accompanying him, if it's all right, sir.

Senator WEICKER. Fine. And you want to identify yourself?

Mr. HARGROVE. Yes, sir, I'm William L. Hargrove, executive vice president.

Senator WEICKER. All right. Mr. Hargrove. Nice to have you too. Proceed. Mr. Canfield.

Mr. CANFIELD. Good morning, Mr. Chairman, I'm Jack Canfield, commissioner of employment security from West Virginia and president-elect of ICESA. I would ask that our written statement be accepted for the record.

Senator WEICKER. It will be included in the record.

[The statement follows:]

STATEMENT OF JOHN A. CANFIELD

My name is Jack Canfield. I am Commissioner of the West Virginia Department of Employment Security and President-elect of the Interstate Conference of Employment Security Agencies, Inc. (ICESA). ICESA is the organization that represents administrators of unemployment compensation laws and employment service offices throughout the country.

On behalf of ICESA I would like to thank you for the opportunity to speak to you today about the state-federal employment security system. We are concerned that both the unemployment insurance system and the employment service are not adequately financed to accomplish their objectives.

Unemployment insurance (UI) is a strong and elastic system; it expands and contracts with the level of unemployment. During this recession it is processing an enormous increase in claims and has implemented three federal extensions of benefits. In spite of these pressures we have managed to process most claims in a timely manner. ICESA is concerned that the system may be a victim of its own resilience. When the number of trained staff is in short supply, quality control procedures must be streamlined or eliminated in order to accomplish the basic claims processing functions. Recent studies by the Department of Labor, completed but not yet released, are likely to show significant problems in the prevention, detection and recovery of overpayments.

The unemployment insurance system requires a flexible administrative funding mechanism because workloads cannot be controlled nor accurately predicted. This necessary flexibility is provided through a system which allocates funds in two separate steps. The first is a base allocation which provides funds for a minimum workload level. The second is a contingency funding mechanism which funds workload experienced above the base level on a quarterly basis.

As this system is administered by the Department of Labor, staff justified by the base workload are expected to be permanent and those justified by above-base workload to be temporary. The temporary staff are funded at a lower average salary rate since temporaries don't receive all the fringe benefits that permanent employees have. In addition, overhead costs are funded at a substantially lower rate for above-base workloads than for base.

This system works fairly well when the base workload is reasonably close to the total and temporaries are hired primarily for seasonal peak workload periods. The system is now functioning with more than half of its claims staff hired on a temporary basis. The revised 1983 budget provides 21,947 permanent staff and 24,041 temporary staff for processing UI claims, determining eligibility, adjudicating appeals and protecting the system from fraud and abuse. Realistically, some of these jobs simply cannot be filled by temporaries because they require extensive training and experience, (e.g., appeals referees and claims adjudications). Therefore, more experienced claims processing personnel are shifted to these jobs, making the proportion of temporaries in the claims-processing jobs even higher.

Such a high proportion of temporary staff results in two major problems. The first and most obvious is lack of experience. Turnover rates among temporary workers is high, often due to state merit system restrictions or union bargaining agreements limiting temporary appointments to a certain period of time, six months for example. In addition, temporary workers often leave on their own as soon as they can find permanent jobs that offer fringe benefits such as health insurance and retirement benefits that temporary positions usually lack. The high number of inexperienced temporary staff means that the permanent staff are under constant pressure, handling the more complicated cases while the temporary staff does the routine work. The permanent staff are often forgoing breaks and working "unofficial overtime" in order to complete their work. This eventually takes its toll in efficiency and accuracy.

The second major problem that results from a high number of temporary staff is inadequate funding for overhead costs. Funds for office space, supplies, computers, supervision and training are provided by the Department of Labor as an add-on to salary and benefit costs per position. A much larger amount is allowed for permanent staff than temporary on the theory that economies of scale are at work. This makes sense up to a point. For example, adding five temporaries to a 20 person local office staff could be accomplished without the need for additional space or another supervisor; when another 15 staff are added, however, the office will be crowded and inadequately controlled. Neither does it make sense that there is less money per position for training when the number of temporaries is high and training is needed the most.

The permanent staffing level for the unemployment insurance program is tied to a level of unemployment expressed as "average weekly insured unemployment " (AWIU). This simply means the average number of unemployment claims filed each week during a year. The permanent staff for FY 1982 was set at a level considered adequate to handle an average of 2.1 million claims per week. We actually processed an average of 4.2 million claims per week. The permanent staff for 1983 remains at the 2.1 level while the Administration projects that an average of 4.5 million claims will be filed. For FY 1984, the President's budget again requests a permanent staff level of 2.1 while estimating the actual number of claims that will be filed at 3.9. This is a significantly lower proportion of permanent staff than the system operated with in the period 1978-1980 as the chart below illustrates.

Fiscal Year	Unemployment Rate	Average Weekly Insured Unemployment (in millions) Base	Total	Base As A Percent of Total
1978	6.2	2.1	2.95	71%
1979	5.8	2.1	2.6	81%
1980	6.8	1.9	2.7	70%
1981	7.3	2.1	3.69	57%
1982	9.1	2.1	4.2	50%
1983	10.2	2.1	4.45	49%
1984	9.3	2.1	3.86	54%

As you can see, we have been operating for several years now with a base level below 70 percent of the total claims level. We have managed to keep the system going by using every short cut we know. This is not the way we want to run the unemployment insurance program. We simply don't have the trained staff to do eligibility interviews; we don't have staff to follow-up on all the possible overpayments uncovered through cross matching wage and benefit files. In many areas there have been long lines. People have had to wait four or five hours to file their claims or resolve some issue connected with it. The system needs help. We hope that it won't be stretched to the breaking point before that help arrives.

We believe that the UI system would be able to provide decent service to the public and ensure the integrity of the system if the base level were increased from the current 2.1M average weekly insured unemployment to 2.8M. This would provide 9,100 additional permanent staff for a total of 31,047 permanent positions. This level would be sufficient to process 73 percent of the FY 1984 claims projected by the Administration. Unemployment is expected to remain high even as we come out of the recession. Therefore, the claims load is not likely to drop below an average of 2.8 million per week. The last time the average was below 2.8M was in FY 1980 when the total unemployment rate was 6.8 percent. The transfer of 9,100 positions from temporary to permanent status will cost $106M, increasing the total FY 1984 budget for unemployment insurance administration by 5.9 percent, from $1.8 billion to $1.9 billion. It is estimated that the system will pay over $32B in benefits in 1984. The relatively small expenditure of $106M could well reduce that $32B by several times $106M, through reduced errors and overpayments.

Mr. Chairman, turning to another major area within the Employment Security System, the Administration's FY 1984 request of $857.8M for Employment Service (Job Service) funding will only sustain the significantly reduced staffing level of 22,800 (excludes DVOP staff) that has been in place since FY 1982. It is important to note that for 15 years prior to FY 1982 the Employment Service (ES) System had 30,000 staffyears. This 21 percent reduction in staff has been damaging to the performance capability of our system. The figures speak clearly to this issue as the following examples[1] will show.

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[1] Found in USES Information Bulletin No. 83-3, dated February 28, 1983.

In FY 1982, nearly 3,026,000 individuals were placed in jobs--a decrease of 18.8 percent from the previous fiscal year. Almost 6.2 million openings were received by the Employment Service in FY 1982--an 18.5 percent drop from the 7.5 million received in FY 1981. Also, job development contacts were made for 1,554,000 individuals in FY 1982--down 20.9 percent from the 1,964,000 contacts of the previous fiscal year. I could go on to describe other areas where direct services have suffered but I believe the point is clear: the 21 percent reduction in Employment Service staffing, beginning in FY 1982, has reduced the service capability of ES by the same magnitude.

Mr. Chairman, I have primarily concentrated on the placement record of our system, but it is also essential for you to recognize that other, very essential, labor exchange services have also been severely reduced. Specifically, as a result of staff reductions in FY 1982, the State Employment Services delivered professional counseling to nearly 701,000 individuals, however this was down 36.1 percent from 1,096,000 counseled during the same period in FY 1981. And I might add that the drop in counseling for veterans was 40.6 percent. In another vital service area, 3.4 percent fewer individuals were tested in FY 1982 compared to the previous fiscal year. As you can see, the reduction in these services is at a much higher level than even those associated with direct placements. The reason is that in meeting the increased demand for all of the services that our system offers, State Employment Service administrators have had to make tough managerial decisions as to which activity or activities would have to be reduced as a result of staff cuts. And although counseling and testing are extremely important tools in assisting job seekers, particularly those who have special problems in entering or remaining in the job market (e.g., youth, female reentrants, and the disadvantaged), the primary emphasis must be placed in assisting the job ready; those individuals who can benefit from our "front-line" staff who perform intake, assessment and referral functions. Quite frankly, we can't even provide enough of these "front-line" staff to meet the demand.

Another extremely important area that is a part of the labor exchange system is the state and local statistical, research and analysis program (labor market information). This program provides the basic information used by educators, business, labor and the employment and training community (including ES) to make vital decisions in areas such as planning, management, and economic development. Unless ES resources are increased, the state and local statistical, research and analysis program will cease to exist and the following types of information will no longer be available: affirmative action data; labor supply/demand and occupational information; wage information, local planning and administrative reports; occupational projections; job development and localized economic information.

We need your help, Mr. Chairman. We need the support of this Subcommittee to recommend a sufficient increase in funds that will enable the State Employment Service system to begin to rebuild its service delivery capability to meet the demand that is upon us right now. The Senate version of the recently passed emergency jobs legislation would have restored approximately 3,300 staff to the states for the remaining months of this current fiscal year at a cost of $50M. On an annualized basis, and considering the increased cost per staffyear for FY 1984, this would amount to $113.4M, and would bring the total FY 1984 request to $971.2M. The staffing level nationwide would move from 22,800 to 26,100, still well below the 30,000 level that existed in FY 1981 and for the 15 years prior to that period. We firmly believe that such an increase to the Allotments to States portion of our budget would be an excellent start in reviving the nation's labor exchange system.

We are not alone in calling for an increase in Employment Service staffing. In addition to the support of organized labor, major veterans organizations and many professional groups, there have been other noteworthy recommendations in this regard. For example, in its final report to the President and the Congress, the National Commission on Unemployment Compensation[2] called for an increase in Employment Service positions to reach approximately 50,000 by 1985. This was based on estimates that there should be at least 4 ES staffyears per 10,000 in the civilian labor force to achieve basic ES goals. Obviously, the civilian labor force has grown significantly since the years that the National Commission compiled its supporting data, and we would have to more than double our current staff to meet the needs that the Commission justified. More recently, the 1983 Joint Economic Report, prepared by the Joint Economic Committee of the Congress, addresses the importance of the Employment Service and the need for adequate resources. To quote from Recommendation No. 20 of the Report:

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[2] Final Report of the National Commission on Unemployment Compensation, July 1980.

> "By producing better matches between workers and jobs, an efficient system of job information and placement assistance will result in higher productivity. It [Employment Service] can save the nation billions of dollars by helping to shorten spells of unemployment and reduce periods of dependence on transfer payments from the government."
>
> "Unemployment insurance offices have endured sharp reductions in permanent staff while the job service was recently denied a much needed increase in personnel. As the long lines of people demonstrate, service to the public has deteriorated. Proper staffing for unemployment insurance and Employment Service offices will help to ensure better information to jobseekers and speed the process of reemployment."

I have attempted, in this portion of my testimony, to justify an increase in staffing for the Employment Service system, based primarily on its role as this nation's labor exchange. However, it is also important to recognize that the Employment Service is legislatively mandated to administer other important programs and activities, critical to the economic improvement of specific segments of the labor force. For example, the state Employment Service is the legislatively designated agency to administer the Targeted Jobs Tax Credit (TJTC) Program. In FY 1982, the ES certified nearly a quarter of a million individuals for this program and vouchered many more as eligible. The $20M provided for the program in FY 1982 (25 percent of which was earmarked for verification) was not nearly enough to do the job required of our system, and placed an additional burden on already reduced ES staffing. The Interstate Conference supports the purpose behind the TJTC program, but encourages this Subcommittee to recommend adequate resources well beyond the $20M requested by the Administration for FY 1984. We believe that an investment of double this size would be necessary, considering the promotional needs of the program and mandate for a costly system of verification.

The ES is also substantially involved in the Work Incentive (WIN) Program, as the administrative entity and/or the provider of employment services. We support this vital program for AFDC recipients and encourage this Subcommittee to continue this productive effort with adequate resources. Your support in the past, despite Administration plans to close the program, has been greatly appreciated.

In addition to TJTC and the WIN Program, the Employment Service by statute is the primary delivery mechanism for veterans employment. ES provides services to veterans on a priority basis and in FY 1982 placed over 400,000 into unsubsidized jobs. While we are proud of this record, this figure is actually a decrease of nearly 20 percent from the FY 1981 level, again due to the staffyear reductions previously addressed. We have a deep commitment to meeting our moral and statutory obligations to veterans, but feel frustrated that the weakening of our system has prevented us from accomplishing this important task. Mr. Chairman, it is not enough to just budget separately for Disabled Veterans Outreach Program (DVLOP) staff and Local Veteran Employment Representatives (LVERs) as the Administration has done in the FY 1984 request. Unless the Allotments to States portion of the ES budget is increased, the essential tools (counseling and testing staff; ADP-job matching; premises, etc.) that are needed by DVOP and LVERs will not be present to support their mission.

In addition, the Employment Service has been called upon to play a significant role in the shaping of each state's comprehensive employment and training system, by virtue of the Job Training Partnership Act (JTPA). Along with the private sector, educational community, state and local officials, and others who have a meaningful role to play in helping to secure employment for our citizens who want to work; the Employment Service System is taking an active lead. Building upon our responsibilities and record as a labor exchange, and recognizing our strong administrative and operational link with the Unemployment Insurance System, the ES is naturally suited to play a lead role in the Title III Program for dislocated workers, as well as in other areas of the Act that require labor market information and basic labor exchange services. We will continue to coordinate our activities with those provided for in the basic training portions of the JTPA, and are encouraged by developments to date.

I would be remiss, Mr. Chairman, if I did not call your attention to the fact that on June 6 of this year, less than 5 weeks from now, the Employment Service will have achieved 50 years of dedicated service to this nation. We are most proud of our record but, quite frankly, this is no time for celebration when so many of our citizens are out of a job and in need of assistance. The only recognition we ask, Mr. Chairman, is to permit us to continue our long history of service with sufficient resources to do the job well.

Mr. CANFIELD. Mr. Chairman, the employment security agencies all across the country are doing an outstanding job in difficult times, helping people find jobs and paying unemployment benefits, but we're stretched to the limit.

There's been an enormous increase in the claims load, as we all know, and the problem in handling that workload, and this complicated formula that we have to deal with, the one used by the Department of Labor with which you're familiar, has left us with too few trained full-time employees and too many part-time, short-term employees.

And it's a formula from which we cannot deviate, we have no flexibility at all to adjust within our budget the numbers of part-time or full-time workers. All we can do with the money we earn is hire part-time help.

And this leaves many of us, and West Virginia is an example, with offices in which 60 percent of our employees are short-term temporary employees who constantly need training in complex unemployment compensation law.

And the only ones who can give that training are permanent employees who have to abandon their duties to train the part-time employees over and over again as we face these dramatic surges in unemployment at the local and county levels.

Nationwide more than one-half of our staffs consist of temporary employees. As a result in every State, administrators find themselves shifting experienced claims personnel to rather technical jobs, and this leaves the proportion of temporaries handling the claims at the front desk even higher.

The result is an increasing number of unemployment claims being processed by employees with little experience, agencies struggling with high turnover because civil service restricts the length of time in which a temporary employee can work, and increased pressure on full-time personnel who are already finding it difficult to cope, because despite all of these handicaps, the Federal Government demands that we, nonetheless, process claims in a timely fashion, which is, of course, something we want to do.

We've used every shortcut in the book, but we're now stretched to dangerous limits. In my own State of West Virginia, for example, in the quarter which ended in December, we processed nearly 1 million claims. In the same quarter last year, 426,000; yet in that same general time period, as we struggled to deal with the claims load that doubled on us, our base staff was cut 20 percent.

Nationwide the permanent staff level is based on handling 2,100,000 claims a week. The fact is in 1982 we handled double that, 4,200,000, and today I understand that figure is at 5,300,000 claims a week.

Yet for fiscal year 1984 the President's budget again calls for a staff level based on 2,100,000 claims, despite projections that the workload will continue to be high.

Mr. Chairman, we would recommend that the 2,100,000 figure be increased to 2,800,000 and that would give us an additional 9,100 full-time staff nationwide and permit us to process 73 percent of the claims load with fulltime staff.

This would cost $106 million and would require an increase in the Unemployment Insurance Administration budget of $1,800,000,000 to $1,900,000,000 and that investment would pay dividends because it would reduce errors and overpayments.

Our second recomendation would relate to job service which has suffered a 21-percent cut since 1981. The administration proposes that we continue job-finding, counseling, and testing services with this vastly reduced staff.

Your Senate version of the emergency jobs bill would restore approximately 3,300 staff to the States. This would have raised us from 22,800 to 26,100. That's still nowhere near the 30,000 level we had for the 15 years prior to 1981, but it certainly would be an excellent start toward reviving the labor exchange system as we move into the Job Training Partnership Act. We have a lot of new duties under that.

And we are supported in this recommendation by the National Commission on Unemployment Compensation and by the Joint Economic Committee of the Congress.

So our request, Mr. Chairman, is basic to do the job well. We would like to have the flexibility to use earned funds for full-time employees in unemployment compensation, not just for temporaries. And in the job service, we must have more employees if we are to continue to help people in this Nation find work.

Senator WEICKER. Mr. Canfield, thank you very much and your statement in its entirety will be included.

Mr. CANFIELD. Thank you, Mr. Chairman.

STATEMENT OF SAMUEL SIMMONS, PRESIDENT, THE NATIONAL CAUCUS AND CENTER ON BLACK AGED, INC.

Senator WEICKER. Our next witness is Mr. Samuel Simmons, president of the National Caucus and Center on Black Aged.

Mr. Simmons, it's nice to have you here. You may proceed.

Mr. SIMMONS. Senator Weicker, the National Caucus and Center on Black Aged welcomes the opportunity to testify at your hearing on the fiscal 1984 Labor, HHS, and Education Appropriations bill.

We shall be brief in our remarks because we know that your time is limited. Our testimony will concentrate primarily on three key areas affecting elderly, blacks, and other aged persons, and that would be title V, the senior citizens employment program; title IV, research, training, and demonstrations; and a nutrition program for the elderly.

First we'd like to commend your subcommittee for its past support of the title V program. The latest example of that was the $37,500,000 funding increase for title V.

This action, coupled with early additional $4,850,000 in the fiscal 1983 supplemental will provide nearly 10,100 more urgently needed jobs for the low-income, unemployed persons 55 years of age and older.

This takes on added importance in view of the fact that today 1,400,000 blacks or about 1 out of 3 aged 55 or over lived in poverty in 1981. In fact, almost 150,000 aged blacks have been added to the poverty rolls from 1979 to 1981, and although we do not have figures from 1982, it's safe to predict that this is increasing.

Title V can be an effective weapon to combat poverty. It provides dignified low-income people with employment opportunities while they help people in the community.

The new funding level will support nearly 62,000 positions. But about 100,000 older Americans are expected to participate in the program. Additional persons can be enrolled because administrative costs are low and very often people are transferred out to private sector jobs.

NCBA urges the subcommittee to approve a funding level to at least maintain the title V program at 62,500 authorized positions on a daily basis.

Ideally, we'd like to see the program expanded because of massive unemployment today that's pushed so many people below the poverty line. We recognize, however, that budget constraints may prevent further funding hikes for the program at this time, although we do believe that an increase is justified and the money would be well spent.

We affirm that the program should be maintained at its current services level, and to the extent possible, the program should be allowed to grow if the budget permits.

A 3-percent funding increase is necessary to maintain the program at its current level. Title V is now based on a $5,111 average cost per enrollee, which is almost entirely made up of wages and fringe benefits.

This figure has not been updated since 1981. During this time the cost of living has risen about 7 percent. Moreover, the title V program will incur additional costs. The social security payroll tax, for example, increases.

One other item I would just like to call to your attention is in terms of cuts that are being proposed in the title IV program. There's no way that the Department will be able to make any kind of positive contribution with an appropriation of $5 million, so we respectfully request your assistance in this as well as in terms of seeing to it that nutrition——

Senator WEICKER. To refresh my memory, by title IV, you are referring to what?

Mr. SIMMONS. Older Americans Act.

Senator WEICKER. And $5 million is for what then?

Mr. SIMMONS. That's for education and training. It's now $22 million. Education, training, and demonstrations.

Senator WEICKER. Of $22 million they propose to cut down to $5 million?

Mr. SIMMONS. That is correct.

Senator WEICKER. For the whole country?

Mr. SIMMONS. For the whole country.

Senator WEICKER. What do you do with that?

Mr. SIMMONS. Not very much. For example, historically black colleges, in terms of what they're doing in the field of gerontology, have been receiving about $1 million, so I think we figured up that there were about 200 beneficiaries of this program, and so actually you'd end up with something where people would just be getting pennies.

PREPARED STATEMENT

Senator WEICKER. All right. Thank you very much and your testimony in its entirety will be included in the record.

Mr. SIMMONS. Thank you.

Senator WEICKER. Thank you, sir.

[The statement follows:]

STATEMENT OF SAMUEL SIMMONS

Mr. Chairman and Members of the Subcommittee, the National Caucus and Center on Black Aged welcomes the opportunity to testify at your hearing on the Fiscal Year 1984 Labor, Health and Human Services and Education Appropriations bill. We shall keep our remarks brief because your time is limited. Our testimony will concentrate primarily on three key areas affecting elderly Blacks and other aged persons--the Title V Senior Community Service Employment Program, Title IV research, training, and demonstrations under the Older Americans Act, and the nutrition program for the elderly.

Senior Community Service Employment Program

First, however, NCBA wishes to commend the Subcommittee for its past support of the Title V SCSEP and other Older Americans Act programs. The latest example is the $37.5 million funding increase for Title V. This action coupled with the earlier additional $4.85 million in the FY 1983 Supplemental Appropriations Act will provide nearly 10,100 more urgently-needed jobs for low-income, unemployed persons 55 or older.

This takes on added importance because 1.4 million older Blacks--one out of every three Blacks 55 or older--lived in poverty in 1981. In fact, almost 150,000 aged Blacks have been added to the poverty rolls from 1979 to 1981. Figures are not yet available for 1982. But, it is safe to predict that poverty will be up sharply for elderly Blacks and other older Americans because of the deep recession in 1982.

Title V, though, can be an effective weapon to combat poverty. Moreover, it has provided a dignified means for low-income older Americans to help themselves while helping others in their communities at the same time.

The new funding level will support nearly 62,500 positions.

But, about 100,000 older Americans are expected to participate in the program. Additional persons can be enrolled because administrative costs are low and many Title V enrollees are transferred into private sector jobs.

NCBA urges the Subcommittee to approve a funding level to, at least, maintain the SCSEP at 62,500 authorized positions on a daily basis. Ideally we would like to see the program expanded because massive unemployment has already pushed many older Americans below the poverty line. We recognize, though, that budgetary constraints may prevent a further funding hike for the SCSEP at this time, although we believe that an increase is clearly justified and the money would be well spent.

Consequently, we reaffirm that the program should be maintained at its current services level. And, to the extent possible, the program should be allowed to grow if the budget permits.

A 3 percent funding increase is necessary to maintain the program at its current level. Title V is now based on a $5,111 average cost per enrollee, which is almost entirely enrollee wages and fringe benefits. This figure has not been updated since July 1981. During that time, prices have risen by about 7 percent. Moreover, the SCSEP will incur additional costs. The Social Security payroll tax, for example, will increase from 6.7 percent to 7.0 percent in January 1984. Further payroll tax hikes are scheduled shortly thereafter--to 7.05 percent in 1985 and 7.15 percent in 1986.

The bottom line is that the average enrollee cost will be, at a minimum, $5,250 in FY 1984. This would require a funding level of $328.125 million to continue the current level of activities.

We fully recognize that the current appropriation exceeds the FY 1984 authorization of $317.3 million. But, it is our understanding that efforts are underway to boost authorizations for programs with appropriations under the emergency jobs legislation exceeding existing ceilings.

NCBA, therefore, reaffirms that Title V should be funded at $328.125 million for FY 1984, which would continue the SCSEP at 62,500 authorized positions.

Title IV Research, Training and Demonstrations

Second, NCBA urges that funding for Title IV research, training and demonstration be increased from $22.175 million now to $26 million. The Administration's $5 million request is simply inadequate and would effectively kill the program.

Title IV has already received deep cuts--totaling 59 percent within a two-year period, from $54.3 million in FY 1980 to $22.175 million in FY 1982.

Our recommended $26 million appropriation would enable the program to function at a more adequate level. The proposal is designed to restore, in a small and fiscally responsible way earlier cuts necessitated by the 1981 Omnibus Budget Reconciliation Act which have crippled Title IV.

NCBA's recommended funding level is nearly equivalent to the fiscal year 1973 appropriation, when research, training and demonstrations received $25 million. If Title IV had kept pace with inflation during this period, present funding would be about $57.5 million.

Title IV can be especially effective during a period of austerity. If funding for basic services is stabilized or reduced, Title IV demonstrations can be a useful tool for services providers to replicate to deliver services most economically to older persons.

Title IV demonstrations can provide important dividends in other ways. These projects can develop innovative models for the AoA network to respond to day-to-day programs confronting older Americans, whether they live in the inner cities, the suburbs or rural areas.

Title IV is also needed to close the shortage of adequately trained personnel to serve the elderly. This is one of the most serious problems in the entire field of aging. NCBA strongly believes that this gap must be closed.

In recent years, services under the Older Americans Act have expanded significantly. A major demand exists for more trained personnel. A $26 million funding level for Title IV is necessary to assure that our Nation will not retreat from this major need.

Nutrition Program for the Elderly

Third, NCBA recommends that the nutrition program for the elderly be funded at least at its FY 1983 level--$319.1 million for congregate meals and 26 million for home-delivered meals.

The Administration claims current services can be maintained because of improved management techniques and higher contributions from participants in the program.

We seriously question the validity of these assumptions. Moreover, we question the wisdom and fairness of higher contributions from the elderly, especially since poverty has increased sharply in recent years. The emphasis on higher contributions may only serve to embarrass or drive away low income elderly persons with the greatest need. This will only compound their misery.

Conclusion

NCBA urges the Subcommittee to adopt these modest proposals to assure that progress continues to be made in responding to the growing problems confronting older Americans. We believe these recommendations are realistic.

They represent a cost effective way to come to grips with serious dilemmas affecting the elderly. We reaffirm our support for these measures and call upon the Subcommittee to approve them.

STATEMENT OF DAVID AFFELDT, LEGISLATIVE COUNSEL, AMERICAN ASSOCIATION OF RETIRED PERSONS

Senator WEICKER. Mr. Dave Affeldt, legislative counsel, American Association of Retired Persons.

Mr. AFFELDT. Thank you, Senator Weicker. I have a longer statement which I shall insert in the record. I'll summarize very quickly our recommendations.

We agree with two of the recommendations articulated by Sam Simmons from the National Caucus and Center on Black Aged. First, we support the funding level for the title V senior community service employment program to maintain the 62,500 positions.

This will be the same number as in fiscal year 1983. However, as Mr. Simmons pointed out, this will require a $328,100,000 funding level, primarily because the cost per enrollee has risen about 3 percent, from $5,111 to at least $5,250.

There are two reasons for this: First, operating costs such as workers compensation, unemployment insurance, and training have increased during the past 2 years, and sharply in some cases, such as workers compensation.

Then, of course, we have the new social security law, which will provide two social security tax increases during the 1984–85 program year. Currently, the rate is 6.7 percent; it will rise to 7 percent for employers in 1984 beginning in January, and then the 7.05 percent in 1985.

If we do not have this 3-percent increase in the funding level for title V, there's a strong likelihood that enrollees will have their hours cut back. We think it would be a tragedy, either to fire low-income title V enrollees or to cut back on their earnings, especially at a time when unemployment has risen by more than 60 percent since April 1981.

There are approximately 803,000 persons 55 or older who are unemployed and another 300,000 who are considered discouraged workers.

Second, we support funding for the nutrition program for the elderly at the fiscal year 1983 levels. This would be $319 million for the congregate meals program and $62 million for the home-delivered meals program.

Certainly AARP favors a $26 million appropriation for the title IV research, training, and demonstration program that is currently funded at $22.200.000. The administration has recommended a $5 million funding level. This would be a 91-percent cut since fiscal year 1980 when the program was funded at $54,300,000.

Our recommended funding level would be roughly equivalent to the fiscal year 1983 appropriation. Since that time inflation has increased by 130 percent, from January 1973 to January 1983.

If you factored in inflation, the funding level for title IV should be at about $57,500,000, so we believe that this is a very reasonable request.

Moreover, we recommend that there be report language to make clear to the administration that national legal services support programs are to be funded, not just the legal services development program or the ombudsman program.

Let me just summarize very quickly our final three recommendations. We recommend $2,500,000,000 for the low-income home energy assistance program, because natural gas residential costs have risen very sharply.

If we are unable to retain this because of budgetary constraints, we recommend $2,250,000,000.

We also support the funding level for the title XX social services block grant at the current operating level and, finally, we recommend a $10 million funding increase for vocational education from $634 million to $644 million.

We urge that this amount be used to promote vocational educational opportunities for persons 55 and over. At present they are greatly underserved.

In conclusion, we recognize that there are many cross pressures upon this subcommittee from various groups affected by the appropriations bill.

We fully realize that every effort must be made to rein in unnecessary spending. We believe, though, that our proposals are reasonable and realistic. And, we urge the subcommittee to adopt them.

One final word. We also want to say that we believe that this subcommittee has acted equitably and very responsibly over the years in making judgments about the many programs that come before it. And we want to thank you for all that you've done on behalf of older persons.

Thank you again.

PREPARED STATEMENT

Senator WEICKER. Thank you very much, Mr. Affeldt. We appreciate it.

[The statement follows:]

STATEMENT OF DAVID AFFELDT, LEGISLATIVE COUNSEL, AMERICAN ASSOCIATION OF RETIRED PERSONS

Mr. Chairman and Members of the Subcommittee, I am David Affeldt, Legislative Counsel for the American Association of Retired Persons.

Our oral testimony will concentrate primarily on Older Americans Act programs and the Low Income Energy Assistance Program. The Association has a longer statement which I have submitted for the hearing record.

I shall summarize the Association's key recommendations because your time is limited.

A. Senior Community Service Employment Program

At the outset, we want to emphasize that the Title V Senior Community Service Employment program should be continued in FY '84 at 62,500 positions.

This is necessary because unemployment remains at near record-breaking levels for persons 65 or older. Most experts expect unemployment to be unacceptably high for the foreseeable future.

Unemployment has increased by 61 percent for individuals 55 or older in less than two years, from 497,000 in April 1981 to 802,000 in February 1983.

These figures only represent the tip of the iceberg because there is a substantial amount of "hidden" unemployment among older Americans, including:

--Persons who have exhausted their unemployment insurance and have stopped "actively" looking for work;

--Individuals who have dropped out of the labor force because they have been unable to locate employment; and

--Persons who have accepted actuarially reduced Social Security benefits before age 65 as a last resort.

Title V is funded at $319.45 million in fiscal year (FY) 1983. However, a three percent increase (which would raise the appropriation to $328.125) is necessary to continue the program in FY 1984 because the average cost per enrollee will increase from the current $5,111 to at least $5,250. The current average enrollee cost has been in effect for almost two years.

Operating costs -- including worker's compensation, unemployment insurance, and training costs -- have increased during the past two years, and sharply in some cases. Moreover, Title V payroll costs will jump in the 1984-85 program year because of two social security payroll tax hikes -- from 6.7 percent currently to 7.0 percent in 1984 and then to 7.05 percent in January 1985.

Unless the per enrollee cost is raised, Title V enrollees may either be terminated or their hours will be reduced. We consider either alternative to be unacceptable.

We, therefore, urge $328.125 million appropriation in FY 1984 for Title V. AARP realizes that this amount is above the current $317.3 million authorization. But the House Education and Labor Committee is considering a number of options to boost authorized funding for several programs which recently received funding increases in the new emergency jobs law above their present ceilings. Title V is included in this group.

We believe that it would be a tragedy to either fire low-income Title V enrollees or to cut back on their earnings. A $328.125 million appropriation will enable the Senior Community Service Employment Program to function at its current level.

B. Other Older Americans Programs

In the interest of time, AARP will summarize quickly other proposals for the Older Americans Act.

We recommend that funding for the nutrition program for the elderly be maintained at the current level -- $319.1 million.

The Administration's proposed $32 million reduction will inevitably reduce the number of meals, despite Administration claims to the contrary.

AARP favors a modest increase in the Title V research, training, and demonstration program -- from the current $22.2 million to $26 million. This is necessary to recover some of the major damage inflicted primarily by the 1981 Omnibus Budget Reconciliation Act.

The $26 million proposal woudl essentially fund the program at its FY '83 level.

Title IV is essential to complement the supportive and nutrition services under Title III of the Older Americans Act. It is also necessary to provide the cadre of trained personnel to deliver service to older Americans, and the body of knowledge to deal with the day-to-day problems confronting the elderly.

Title IV has yielded impressive dividends for a relatively small expenditure. Demonstrations and special projects have paved the way for innovative programs and concepts that have helped to strenghen the Older Americans Act.

Key examples include the nutrition program for the elderly, Foster Grandparents, RSVP (Retired Senior Volunteer Program), Area Agencies on Aging, the "Over Easy" television series, the long-term care gerontology centers programs, the minority intern program, and others.

AARP also believes that Title III-B supportive services should, at a minimum, be continued at its current operating level, and preferably higher if the budget would permit. Title III-B operates at about $251.5 million in FY '81. Operating costs, of course, have increased since then, even though inflation has moderated recently.

C. Low Income Home Energy Assistance Program

In the area of energy assistance, AARP urges that the appropriation for the Low Income Home Energy Assistance Program (LIHEAP) be raised from its current level of $1.975 billion to $2.5 billion. This authorization figure was proposed in legislation introduced by Senators Danforth and Eagleton during the Lame Duck session and is now embodied in legislation under serious consideration in the House.

LIHEAP has become an increasingly critical program for low income persons as home fuel prices -- particularly natural gas -- have continued their relentless climb. While heating oil prices have stabilized recently, natural gas prices have risen over the past year by an average 25 percent nationwide, and as much as 60 percent or more in some states. There is no reason to expect a change in this trend in the year ahead. Over half of all older Americans, it should be noted, rely on natural gas for home heating. Low income people are simply in no position to absorb price increases of this magnitude.

Appropriations for LIHEAP have been inadequate from the beginning, but never more so than this year. The program can only stretch its dollars to about a third of those eligible, and the amount of assistance to households that do receive it (33% of which are occupied by elderly persons) has dropped in most states to less than what it was two years ago. Moreover, the number of applications for aid this year far exceeds the level of demand last year -- and this despite a warmer-than-usual winter.

Both the Fuel Oil Marketing Commission (FOMC) and the Committee for Economic Development (CED) have estimated that a level of aid commensurate with need would be in excess of $5 billion per year. Although $2.5 billion is clearly inadequate to meet this need, it would be a significant improvement over the FY 83 level and is realistic in view of current efforts in Congress to raise the authorization level. We urge the Committee to support $2.5 billion and in any case to support no less than the $2.25 billion assumed in the House Budget Resolution.

D. Other Programs Affecting Older Americans

On other fronts, AARP recommends that the vocational education appropriation be increased by $10 million, from $634 million to $644 million. We urge that this amount be used to promote vocational education opportunities for persons 55 and older. At present, they are greatly underserved.

The Title XX/Social Services Block Grant (SSBG) is currently operating under an appropriation of $2.67 billion, a combination of full funding under a regular appropriation and an additional $225 million provided through recent jobs legislation. AARP recommends that this combined appropriation level be maintained in FY 1984. This is still considerably less than the $2.9 billion level that Title XX had prior to conversion to a block grant.

The SSBG is important to low income persons generally, and is especially important to the elderly. Services provided through the program are essential to prevent premature institutionalization, allowing older Americans to continue to lead lives of dignity and independence in their own homes as long as possible. Services provided under SSBG, such as homemaker/home chore, adult day care, transportation, and home delivered meals, have been cut back significantly in the past two years -- not only because of overall funding reductions, but also because the allocation of dollars has shifted somewhat away from programs targeting the elderly. The Office of Management and Budget has estimated that in FY 1981 about $575 million in Title XX funds -- or 21 percent of total program dollars -- benefited the elderly. In FY 1982, however, only $394 million of social service block grant funds -- or 16 percent of the total -- were estimated to directly benefit older Americans.

Current widespread unemployment and economic distress have contributed to problems social services are intended to help alleviate. AARP believes that the interests of both program participants and those newly employed in providing social services are best served by continuing funding in FY 1984 at $2.67 billion.

E. Conclusion

AARP recognizes that there are many cross pressures upon this Subcommittee from various groups affected by the Labor, HHS and Education Appropriations bill.

We further realize that every effort must be made to rein in unnecessary spending. We believe, though, that our proposals are reasonable and realistic. And, we urge the Subcommittee to adopt them.

STATEMENT OF JAMES G. BOURIE, DIRECTOR, NATIONAL ECONOMICS COMMISSION, THE AMERICAN LEGION

ACCOMPANIED BY PAUL S. EGAN, DEPUTY DIRECTOR, NATIONAL LEGISLATIVE COMMISSION, THE AMERICAN LEGION

Senator WEICKER. Mr. James Bourie, director, National Economics Commission of the American Legion, accompanied by Paul Egan, director of the national legislative commission of the American Legion.

Mr. EGAN. Jim Bourie will summarize our statement. I think there's no way to say that it's particularly gratifying to appear before you this morning. Both of us originally hail from your home State, Connecticut.

Senator WEICKER. That's great. Whereabouts?

Mr. BOURIE. Woodbury.

Senator WEICKER. Why did you leave?

Mr. BOURIE. We're wondering that ourselves.

Mr. Chairman, the American Legion wishes to thank you for this opportunity to present its views on appropriations as they affect veterans employment programs.

Pertinent resolutions adopted by the American Legion are attached. with the request that they be made part of the record.

The Office of the Assistant Secretary for Veterans Employment within the Department of Labor is the principal adviser to the Secretary on veterans' employment training matters. It is one of the smallest Department components, having only 228 personnel, 17 in the national office and 208 field representatives.

Yet that office is charged with a heavy responsibility toward all veterans; especially toward Vietnam era veterans and disabled veterans. With unemployment rates at record levels, the Office of the Assistant Secretary must have the necessary funds to respond to the employment and training needs of this country's veterans.

The Department of Labor for fiscal 1984 has proposed a $9,600,000 budget for the Assistant Secretary's office. This amount in our estimation will sustain the 228 positions for fiscal 1984 with no disruptions of personnel or services.

However, included in that amount is $535,000 for travel funds, the same as fiscal 1983. One of the consistent complaints heard by the American Legion from veterans employment and training service personnel is the lack of adequate travel funds, especially in rural areas. It is not uncommon for State and assistant State directors of veterans employment to expend their own funds without reimbursement.

It becomes more critical, Mr. Chairman during these times of high unemployment when field representatives must be on the move making contact with employers, potential employers, veteran outreach efforts and the like.

Also responding to the employment and training concerns of veterans is the disabled veterans outreach programs—DVOP—specialist. That program for fiscal 1984 is proposed at $62,600,000, and from all accounts there will be no disruption of veterans services or loss of personnel through lack of proposed funding.

Like the DVOP specialist, local veterans employment representatives—LVER's—are in the front line of veterans employment training services. To sustain the LVER's, $46,200,000 is needed for fiscal 1984, which would have no detrimental effect on veterans' services, and the Department of Labor has so proposed that funding amount.

One point must be made here, Mr. Chairman. Both the disabled veterans outreach progam and the LVER's are funded from the State employment security budget, more specifically, the Federal unemployment trust account of the State employment security agencies.

As you know, for well over 10 years the State employment security agencies have had imposed a 30,000 personnel ceiling which over the years has consistently been reduced while having to respond to an ever-demanding labor market.

The Department of Labor has proposed the SESA's at $857 million for 24,800 staff, but it must be remembered that of the staff figure, over 3,000 personnel are devoted to veterans services. DVOP's and LVER's, and they can only serve veteran clientele, but they are used for other services.

That concludes our testimony. We do want to make mention of three things and one represents a bit of departure from this committee; it's on the Small Business Administration.

Last year through your leadership, $3 million was devoted to the SBA's veteran outreach efforts and they are doing a tremendous job with that, we're getting very favorable reports around the country. And unfortunately the SBA has not proposed anything for 1984, so our fear is that this program is suddenly going to stop dead and we need some transition.

Senator WEICKER. I discussed that very situation yesterday in the Subcommittee on State, Justice, and Commerce when we had the appropriations hearings on SBA, and we'll keep an eye on that.

Mr. BOURIE. Thank you very much, because as I said, very favorable reports are coming back——

Senator WEICKER. Well, some favorable, some not favorable. That's what got me into it originally. It's a mixed bag—I still think a better job can be done at SBA.

Mr. BOURIE. Indeed. Well, if there's anything we can do, certainly call on us, because we have been in touch and we have involved ourself in some demonstration projects around the country.

The other point is, you heard earlier from ICESA and the impact of the budget cuts to them. Well, when they catch a cold, the Veterans Service get pneumonia. In the job service, for example, since fiscal 1981 veteran placements are off by 20 percent, and veteran counseling is off by 35 percent.

So there is a definite impact when their budget is cut for the job service, and we certainly support their request for additional funding and staffing.

In all, what the Department of Labor has proposed for the Veterans Service is in our estimation adequate. It is a bare bones minimum. And we can live with that. We're not requesting any more money.

PREPARED STATEMENTS

Senator WEICKER. Thank you very much, both of you. We will place your statement in the record, as well as other statements submitted for the record on appropriations for the Department of Labor.

Mr. BOURIE. Thank you.

[The statements follow:]

STATEMENT OF PAUL S. EGAN

Mr. Chairman and members of this subcommittee:

The American Legion wishes to thank you for this opportunity to present its views on appropriations as they affect veterans employment matters. Pertinent resolutions adopted by The American Legion are attached, with the request that they be made part of the record.

The Office of the Assistant Secretary for Veterans Employment (ASVE) within the Department of Labor is the principal advisor to the Secretary on veterans' employment/training matters. For comparison, it is one of the smallest department components, having only 228 personnel, seventeen in the national office and 208 field representatives. Yet, that office is charged with a heavy responsibility towards all veterans; especially towards Vietnam era veterans and disabled veterans. With veteran unemployment rates at record levels, the Office of the Assistant Secretary for Veterans Employment must have the necessary funding to respond to the employment/training needs of this country's veterans.

The Department of Labor for fiscal 84 has proposed a $9.6 million budget for the ASVE. This amount will sustain 225 positions for fiscal 84 with no disruption of personnel.

However, included in that amount is $535,000 for travel funds, the same as fiscal 83. One of the consistent complaints heard by The American Legion from Veterans Employment and Training Service (VETS) personnel is the lack of adequate travel funds, especially in rural areas. It is not uncommon for State and Assistant State Directors of Veterans Employment to expend their own funds without reimbursement; indeed, it is almost an unwritten rule that if you're a Veterans Employment and Training Service field representative, you will use your own funds.

It becomes more critical, Mr. Chairman, during these times of high veteran unemployment when field representatives must be on the move making contact with employers, potential employers, veterans outreach efforts, and the like.

Also responding to the employment/training concerns of veterans is the Disabled Veterans Outreach Program (DVOP), where 2,012 state employees are located in local Job Service offices and elsewhere. That program for fiscal 84 is proposed at $62.6 million. And from all accounts, there will be no disruption of veteran services or loss of personnel through lack of funding. Like the DVOP specialists, local veterans employment representatives (LVERs) also are in the front line of veterans employment/training services. They number approximately 2,000 full and part time state employees located in designated Job Service offices. To sustain the LVERs, $46.2 million is proposed for fiscal 84, which, again, should have no detrimental affect on veterans services.

One point must be made here, Mr. Chairman. Both the Disabled Veterans Outreach Program and Local Veterans Employment Representatives are funded from the State Employment Security Agencies (SESA) budget; more specifically, the Federal Unemployment Trust Account. For every dollar increase to veterans services, there is a corresponding loss to the SESA. And, as you may know, for well over ten years the SESAs have had imposed a 30,000 personnel ceiling which over the years has consistently been reduced while having to respond to an ever demanding labor market. The Department of Labor has proposed the SESAs at $857 million for 24,800 staff, but it must be remembered that of that staff figure, over 4,000 personnel are Disabled Veterans Outreach Programs specialists and Local Veterans Employment Representatives who serve only veterans. Thus, the SESA is reduced to only 20,800 nationwide personnel.

The American Legion for one would like veterans services to be funded from General Revenues for obvious reasons. We do not want veterans services funded to the detriment of other programs. In any event, the $108.8 million for veterans services should be added to the SESAs overall budget for staff and other necessary costs. It is fundamentally unfair and inequitable for the Department of Labor to force the SESAs to absorb the cost of veterans services in addition to their own reductions.

SIXTY-FOURTH ANNUAL NATIONAL CONVENTION
OF
THE AMERICAN LEGION
AUGUST 20-26, 1982
CHICAGO, ILLINOIS

RESOLUTION NO.: 257

COMMITTEE : ECONOMICS

SUBJECT : FULL FUNDING FOR THE OFFICE OF THE ASSISTANT SECRETARY FOR VETERANS EMPLOYMENT

WHEREAS, PL 96-466 established the office of Assistant Secretary for Veterans Employment, to coordinate and direct all veterans employment/training activities within the Department of Labor; and

WHEREAS, In order to fully implement those pertinent sections of title 38, USC, as regard veteran employment matters, the office of Assistant Secretary for Veterans Employment must be fully funded; and

WHEREAS, Underfunding of the office of Assistant Secretary for Veterans Employment will have a negative impact on the employment/training delivery services to all veterans, especially those of the Vietnam era; now therefore be it

RESOLVED, By The American Legion in National Convention assembled in Chicago, Illinois, August 24, 25, 26, 1982, that the office of Assistant Secretary for Veterans Employment, U.S. Department of Labor, be fully funded to carry out its mission as prescribed by law and regulation.

RESOLUTION NO.: 261

COMMITTEE : ECONOMICS

SUBJECT : SEEK INCREASE IN STAFF FOR STATE EMPLOYMENT OFFICES

WHEREAS, The Employment Service has been in existence since 1933 providing free job assistance to unemployed persons; and

WHEREAS, One of the primary functions of the Employment Service is to provide veterans with an effective priority service; and

WHEREAS, The Employment Service budget has been severely curtailed in spite of an increase in the size of the labor market and a substantial increase in the use of the Employment Service by employers and unemployed persons during the past several years; and

WHEREAS, This huge increase in services requires additional staff and offices throughout the United States in the Employment Services to maintain and improve employment services for veterans and all other applicants; now therefore be it

RESOLVED, By The American Legion in National Convention assembled in Chicago, Illinois, August 24, 25, 26, 1982, that Congress and the Department of Labor be requested to support an increase of positions in the State Employment Services to a number commensurate with the increase in the labor force so that an effective employment service, including employment services to veterans, can be maintained.

RESOLUTION NO.: 461

COMMITTEE : ECONOMICS

SUBJECT : ADEQUATE FUNDING AND ACCOUNTING OF FUNDING FOR THE DISABLED VETERANS OUTREACH PROGRAM

WHEREAS, Congress made permanent the Disabled Veterans Outreach Program with the enactment of PL 96-466 (38 USC 2003A); and

WHEREAS, Appropriations for the program are authorized under title 42, Section 1101, United States Code; and

WHEREAS, Under that authorization are all employment activity services, but not identified as specific line item budget amounts within the Department of Labor's office of Assistant Secretary for Veterans Employment; and

WHEREAS, Such fiscal grouping of programs may cause other programs to be funded to the detriment of the Disabled Veterans Outreach Program; and

WHEREAS, Such fiscal groups of programs provides no fiscal control and accountability of the Disabled Veterans Outreach Program; now therefore be it

RESOLVED, By The American Legion in National Convention assembled in Chicago, Illinois, August 24, 25, 26, 1982, that Congress and the Department of Labor be urged to provide the Disabled Veterans Outreach Program with specific and separate line item budget requests, and be it further

RESOLVED, That the office of Assistant Secretary of Labor for Veterans Employment be urged to implement an effective administrative control mechanism to ensure Disabled Veterans Outreach Program funds are utilized for the intended purpose.

STATEMENT OF ROBERT MULLINS, DIRECTOR OF LEGISLATION, NATIONAL FARMERS UNION

Mr. Chairman and Members of the Committee:

We appreciate the opportunity to present this statement in support of FY 1984 appropriations for the Senior Community Service Employment Program, Title V of the Older Americans Act. National Farmers Union is proud to sponsor Green Thumb which is the oldest and largest program for employment of older workers under SCSEP in providing needed community services in 45 states across our nation.

We want to thank you on behalf of Green Thumb workers and rural communities from Maine to California for your continuing support of the older worker program. When Congress overrode the veto of FY 1982 Supplemental Appropriations Act last September, Green Thumb was able to maintain the jobs of 17,826 older persons and the essential community services in over 1,826 counties in which Green Thumb operates. Once again, your continued commitment to the program was demonstrated a few weeks ago when you enacted H.R. 1718, the Emergency Jobs Appropriations Bill, which included $37.5 million for Title V. This allows 7,500 additional older workers the opportunity to work.

I want to emphasize the importance of relying on the experienced staff of organizations such as Green Thumb, who are already in place and ready to move rapidly to implement the desire of Congress and use these emergency employment funds to help the economic plight of older men and women.

The experienced staff who administer the Senior Worker Program are an important national resource and have established mechanisms to quickly recruit the additional workforce. Green Thumb can and will be ready July 1 to fully implement its charge of employing these senior workers who will provide the desperately needed services in hundreds of communities throughout Rural America.

In 1965, when we received our first grant to hire 280 workers in four states for rural community beautification, there were no staff people who had experience in providing part-time employment for economically disadvantaged older men and women. Too often employment programs had been focused on opportunities for younger workers or for unemployed skilled mid-life workers. Now we have a cadre of people who have pioneered in the field of not only recruiting people who have become discouraged and convinced that there is no place in society for them but also in finding the community organizations who can provide the sponsorship for the wide variety of services which are delivered by these workers.

I am proud to attach to this statement the Quarterly Progress Report which Green Thumb submitted to the Department of Labor on our Title V activities as of December 31, 1982. This not only reflects the age, sex, race and education of our workers, but it also outlines the wide variety of services which they deliver. You will notice that about 60 percent of the workers serve their communities at large and some 40 percent provide help specifically to deliver senior citizen services.

As you know, the Senior Worker Program has always had as one of its goals the development of job opportunities so our workers can move into private employment. Although we have always tried to serve the oldest and the most disadvantaged, we have continued to emphasize the training and assistance to help them make that move back into private employment.

Congress has directed increased emphasis on expanding these efforts, and we are proud to report that last year across the nation Green Thumb placed 17-1/2 percent of their workers into private employment. Some of these men and women transfer to the payrolls of the sponsoring agencies they were assisting. Others have moved on to other unsubsidized jobs within their local communities. They have all provided a living demonstration of the viability of hiring older workers.

We do not expect that now or in the future all or even a majority of our workers would move into private employment. Recognizing the high unemployment level among all age groups and the rapidly changing technology of the job market, we believe our nation has a responsibility to provide employment opportunities to the targeted population. You will note on the attached chart that over 10,000 of our 16,447 positions are held by people over 65 years of age (62%). Also, 7,755 had less than an eighth grade education and a total of 11,672 have eleventh grade education or less. Many of these people have valuable skills to contribute to an employer, but they often find it difficult to locate job opportunities.

During the last decade, Green Thumb has placed some of their workers in the offices of the Employment Service to serve as specialists in developing and targeting employment opportunities for older workers and, as a direct result, have helped hundreds of older men and women to take their place in the productive work force of our nation. The attached chart shows that some 300 Green Thumb workers are now providing employment assistance.

Three percent of the funds provided in the FY 1982 appropriations for Title V were earmarked to be used in special efforts to place workers in private employment. Green Thumb has set up some special programs to demonstrate the ways in which we might provide additional training to our workers and assist them in this transfer. Six of our Green Thumb states were selected, on a competitive basis, to receive special project funds to mount innovative training programs.

California Green Thumb has established classroom and work experience programs for home health aids and high technology assembly work.

New Jersey Green Thumb has provided classroom and work experience programs in word processing and is placing older workers with a large federal credit union.

Oklahoma Green Thumb has worked with a vo-tech school to develop special courses on home health care and nurse's aid training. They will work with private nursing homes and hospitals to assure the maximum opportunity for placement on both full-time and part-time jobs when the workers graduate.

South Dakota Green Thumb has developed a work experience program for factory assembly jobs.

Tennessee Green Thumb has also developed classroom and work experience in health care and placed 18 of the 27 participants in their first class. They started their second class on April 4.

Utah Green Thumb is also developing a program to help train home health workers. You recognize from recent hearings on health care costs that it becomes increasingly important to have a trained supply of para-professional health care workers.

The opportunity to train older workers in the rapidly growing computer software field will provide another demonstration of the flexibility and competence of older men and women. I was told by a friend associated with a large computer firm that many industry people working in the fields of recruitment and training for the computer field question whether middle-aged and older workers can be retrained in the hi-tech field. I believe one of our important contributions through this increased emphasis on private placement will be to convince industry of the rich reservoir of potential staff that is waiting for them.

We have provided members of your committee with a copy of the Green Thumb Annual Report for 1982 which outlines both statistical information and reports on a few of the kinds of service which older workers are delivering. We certainly hope that each of you and your staff, when possible, avail yourselves of the opportunity to visit in your own state Green Thumb and other Title V projects so that you can see for yourselves the continuing variety of assistance that they provide.

In your consideration of FY 1984 appropriations, we hope you will find it possible to continue at least the present level of FY 1983 funding, now almost $320 million. Although this is scheduled to provide 62,500 job opportunities, we recognize that this barely begins to provide opportunities for the very large number of those men and women over 55 years of age who are unemployed, who both want and need to work to supplement their limited income and who have a lifetime of skills and experience to deliver to their communities. We recognize that this appropriation is slightly over the $317.3 million authorized for FY 1984 in the Older Americans Act Amendments of 1981. We hope that appropriate action will be taken to provide the necessary budget clearance and to assure the authority for such continuing funding.

In closing, let me say that we were deeply disappointed in the President's Budget Recommendation to transfer the Senior Community Service Employment Program from the Department of Labor to the Administration on Aging. We outlined our views to the House Aging Subcommittee on Retirement, Income and Employment on this proposal. SCSEP is an employment program. It serves the community at large. It needs to be in the agency that administers employment programs -- the Department of Labor. We believe that report language carried in the House and Senate Conference Report of the Emergency Jobs Bill made clear the Congressional intent that the program continue to be administered in the Department of Labor.

I wish there were time and opportunity to visit about all the interesting and innovative ways in which older men and women are using their skills and their commitments for their communities. I recognize that your time is limited and that your understanding is great. We wish again to extend our appreciation to you for your continued support and commitment to older men and women across the nation and their desire to continue to lead useful, productive lives in their community.

OMB Approval No. 44-R1608

U.S. DEPARTMENT OF LABOR • Employment & Training Administration

SENIOR COMMUNITY SERVICE EMPLOYMENT PROGRAM - QUARTERLY PROGRESS REPORT

PROJECT SPONSOR Green Thumb, Inc.	REPORT PERIOD ENDING (Month & Year) December 31, 1982		PROGRAM NO. 41
CITY AND STATE Arlington, Virginia (Summary)			TYPE OF REPORT (Check One) ☒ Interim ☐ Final
AGREEMENT NUMBER 99-1-093-11-26	SUBPROJECT NO. 00	PROJECT PERIOD From July 1, 1981	To June 30, 1983
NO. ENROLLMENT POSITIONS ESTABLISHED ➤ ➤	16447	UNSUBSIDIZED PLACEMENT GOAL ➤ ➤	3640

A. ENROLLMENT LEVELS (Number of Enrollees)

1. Carried over from previous project	16807	3. Placed in unsubsidized employment this project	3a 4743	3b 1/ 312	5. Current enrollment (End of Period)	17826
2. Started under this project	11571	4. Other terminations this project	5809		6. Enrollment vacancies (End of Period)	28

B. JOB INVENTORY

SERVICES TO GENERAL COMMUNITY	NO. JOBS	SERVICES TO ELDERLY COMMUNITY	NO. JOBS
1. Education	3262	11. Project Administration	340
2. Health and Hospitals	704	12. Health and Home Care	545
3. Housing/Home Rehabilitation	471	13. Housing/Home Rehabilitation	690
4. Employment Assistance	299	14. Employment Assistance	177
5. Recreation, Parks, and Forests	1413	15. Recreation/Senior Centers	1141
6. Environmental Quality	637	16. Nutrition Programs	2101
7. Public Works and Transportation	1837	17. Transportation	398
8. Social Services	1193	18. Outreach/Referral	835
9. Other	1574	19. Other	209
10. TOTAL (1 - 9)	11390	20. TOTAL (11 - 19)	6436

C. ENROLLEE CHARACTERISTICS

CHARACTERISTICS		STARTS (Cum.)	CUR. ENROLL.	CHARACTERISTICS		STARTS (Cum.)	CUR. ENROLL.
SEX	Male	5329	7208	RACE/ETHNIC GROUP	White (not Hispanic)	9495	14209
	Female	6242	10538		Black (not Hispanic)	1219	2459
EDUCATION	8th & Under	4187	7755		Hispanic	576	682
	9th - 11th	2494	3917		American Indian/ or Alaskan Native	239	416
	High School Grad or Equivalent	3571	4559		Asian or Pacific Islander	42	60
	1 - 3 years College	976	1237	AGE	55 - 59	4014	2974
	4 yrs. College or more	343	358		60 - 64	3540	4631
Family Income at/below Poverty Level		8552	15170		65 - 69	2161	4404
Veteran		2389	2619		70 - 74	1249	3475
D. AVERAGE HOURLY WAGE/CURRENT ENROLLMENT		$3.39			75 and Over	607	2342

E. NARRATIVE REPORT (Attachment)	SIGNATURE	DATE

(Formerly MA 5-140) 1/ Persons placed in supplemental jobs but not terminated from the program ETA 5140 (Rev. May 1978)

STATEMENT OF THE AMERICAN FEDERATION OF STATE, COUNTY AND MUNICIPAL EMPLOYEES

The American Federation of State, County and Municipal Employees (AFSCME), representing more than one million employees in state and local governments and in non-profit and federal agencies, submits the following statement for the record on FY '84 Labor-HHS appropriations.

The last few years have not been easy for either our members, who work in the programs under the Subcommittee's jurisdiction, or the people they serve. Since 1979, the national unemployment rate has almost doubled. More than 13 million workers are officially jobless or have dropped out of the workforce.

Joblessness has destroyed the economic and social stability of millions of Americans. Increases in homelessness, domestic violence, child abuse, infant mortality, charity care in public hospitals and the spread of soup kitchens are grim indicators of the human toll unemployment has taken.

At the same time that the ranks of the poor and helpless have swollen to almost unprecedented levels, the recession has deprived state and local governments of the revenues necessary to help the needy. Their problems have been further compounded by illogical and disproportionate funding reductions in the means-tested entitlement programs and in domestic discretionary programs, many of which fall within your jurisdiction. These cuts, totaling $57 billion since 1981, together with other revenue losses left state and local governments with a combined deficit of $4.6 billion in 1982.

As a result, 425,000 state and local government jobs vanished in the two years since January 1981. According to Data Resources, Inc. this decline was proportionately greater than the drop in private sector employment in the same period. During those two years, Ohio abolished 29,000 state and local government jobs; Kentucky 7,300; Massachusetts 30,200; Wisconsin 2,300; Connecticut 4,300; and Michigan 42,500. In 1982, 1,000 state jobs were lost in Oregon and 1,200 in Illinois. The list could go on and on.

All the indications are that the fiscal condition of state and local governments will only worsen this year. For example, an Associated Press survey predicts that state deficits alone will total $5.7 billion for FY 1983. In addition, the Immigration bill moving through Congress could add substantially to the fiscal burdens of state and local governments by legalizing undocumented immigrants in the United States. Without adequate federal assistance, they may have to pick up a substantial share of the $3.9 billion in increased services to which OMB has estimated the immigrants will be entitled between FY84-87.

It is no exaggeration to state that these cuts have brutalized public services. Tragically, at the very time that the need for vital human services in employment, social services and health care is the greatest, state and local governments find themselves the least capable in decades of providing them. This situation not only has created great frustration and low morale among the public employees who are left trying to respond to the immense needs of the victims of this recession. It also has weakened the quality of public services and in some cases undermined program objectives.

Perhaps no where is the gap between government action and need more dramatic than in the area of employment. In the late 1970's, before the onset of the current recession, the federal government was spending more than $10 billion on public service employment and job training under CETA; maintained 30,000 positions under the Employment Service; and supported WIN at $365 million. Today, with unemployment at the highest levels since the Great Depression, the Administration is requesting $3.6 million for employment and training activities, $857.8 million to support the 22,800 Employment Service positions (excluding DVOP staff), the abolition of the already reduced WIN program in favor of mandatory workfare, and cuts in state labor market information.

In the absence of a public service jobs program, we should at least provide adequate resources for those federal programs which can facilitate the efforts of the unemployed to find work and help them adapt to the dramatic technological changes occurring in the economy.

With the exception of the new displaced worker program, the Administration's FY'84 requests fail to reflect these objectives. Even the proposed increase to $240 million for the displaced worker program falls far short of the resources needed to retrain the thousands of private workers who have lost their jobs because of plant closings and mass layoffs. And there are major dislocations occurring in the public sector, especially in mental health and retardation, which also demand attention.

AFSCME strongly rejects the Administration's proposal for mandatory workfare. It is based on the punitive and erroneous notion that those on welfare do not want to work and must be forced to do so. From a more practical viewpoint, workfare has proven to be costly and complicated to administer and can result in the displacement of already-employed public employees in the lower skilled jobs. It seems totally counterproductive to us to institute a program that will force greater cost burdens on state and local governments and that may cause employed workers to lose their jobs.

Strengthening job training programs, the WIN program and the Employment Service, which help the unemployed find private sector jobs is a far better alternative. The Employment Service, as you know, provides general labor exchange services to both employees and employers. A study not yet released by the Labor Department has found it to be of particular benefit to women and older men. The WIN program provides similar services directed specifically to welfare recipients.

We at AFSCME deeply appreciate the support the Subcommittee gave to these two programs last year. Without your help, WIN would not have survived, and the Employment Service would have plunged to so low a level that it virtually would have collapsed.

We are picking up some evidence that WIN has begun to stabilize. Last year's restoration of WIN funds combined with some very modest improvements in the economy, are showing up in Wisconsin's job placement figures. Last November placements totaled 497 statewide compared to 835 the year before. In December only 341 people were placed compared to 728 the previous year. This March, however, placements rose to 616 compared to 401 in March, 1982.

However, WIN continues under enormous strain. Both the continual uncertainty about its fate and its marginal funding level have made it difficult to maintain a strong program. In Ohio, for example, WIN placements plunged from 22,430 between October '80 and September '81 to 7,199 between October '82 and March '83. In the Cleveland East office, only two people were placed in jobs during the six month period ending last March, compared to 43 people the previous year. In addition, it is reasonable to speculate that the recent welfare caseload increases are intensifying pressures on the program, which, by law, must register all eligible welfare recipients for work.

The deterioration in Employment Service funding has crippled its ability to perform. Its current staff level is just at the system's viability point according to one internal Labor Department document. Placements in FY 82 declined by 18.8 percent. While some may attribute this drop to the lack of available jobs, the dramatic decline in job development contacts and job counseling, which affect job placement rates, can only be attributed to reduced staff capacity combined with a huge increase in job seekers. In Joliet, Illinois for example, the local Employment Service office now handles 800 job seekers a day when a high day used to be 300. The office has three professional staff less than a year ago, and job developers are pinch hitting to get the simple processing done. The picture is the same in Wisconsin where between FY 81 and FY 82 placements dropped by 30 percent; employer contacts fell from 54,006 to 29,286; and the number of clients counselled plummetted from 60,438 to 9,225. The last six months have shown little improvement over FY 82, although in the last month or two a very modest increase in placements has occurred as the economy began to pick up slightly. Staff morale, while improving, still is not as good as it was before the cuts.

No one expects unemployment to fall to the 1979 level any time soon, but the current modest signs of recovery mean that additional employment opportunities may be available. Proper staffing for the Employment Service, according to the 1983 Joint Economic Report, can speed up reemployment and reduce dependency on government assistance programs. An unpublished study commissioned by the Labor Department concludes that the Employment Service is an efficient use of public resources. Adequate funding for WIN, in concert with the Job Training Partnership Act can offer real employment opportunities - not just workfare - to welfare recipients.

Although funds for Unemployment Insurance, the other part of the Employment Security system, have increased as workloads have increased, other factors have combined to put considerable strain on that program as well. Because Employment Service and Unemployment Insurance activities are often co-located, the Employment Service cuts that caused office closings, also have meant fewer offices to handle Unemployment Insurance claimants.

Equally significant, the increased funds have been used to hire temporary rather than permanent staff. These temporary or intermittant staff now out number permanent staff. According to our union members as well as program administrators in several states, this situation is having a detrimental affect on the system. In Ohio, we have been told, there is considerable turnover among the intermittants who have no training and little, if any, long term commitment to the program since their appointments are temporary and they receive no employment benefits. Our local union representatives in Wisconsin echo the same theme. In that state, while the number of claims in week sixteen of this year was actually lower than the same week a year ago, the number of first payments within two weeks of the week of application declined by 8 percent from 88.4 percent to 80.4 percent. Part of the reason for this drop, they believe, are rapidly changing rules and formulas under the Federal Supplemental Compensation programs. It is hard enough for trained staff to keep up, much less untrained personnel, they point out. The result has been a backlog of benefit rate interviews and increased adjudications. Many adjudicators are working overtime to try to keep up. We have heard similar comments in Connecticut where administrators also have told us that intermittant personnel turn over rapidly don't work as fast as permanent employees, can't answer questions as quickly and make more mistakes. Long lines and waits of up to three hours reported by the press in Champaign, Illinois this March are symptomatic of the same problems.

The gap between needs and resources is no less in the programs that provide non-economic assistance to the poor and unemployed.

Unemployment clearly has driven up the incidence of child and spouse abuse and homelessness. A survey last fall by the National Committee for Prevention of Child Abuse reported an increase in reported child abuse cases over the previous year in 39 states. Congressional testimony earlier this year documented increases in child abuse and neglect corresponding to increases in unemployment in Wisconsin Counties. Kentucky families who have never sought help are seeking social service assistance. The Social Services Department is greatly concerned about the increase in abuse cases and feels it may be due to increased stresses caused by unemployment. In Peoria, the number of women with unemployed husbands seeking help at a shelter for battered women rose from 33 percent to 70 percent after a local brewery closed. Protective service cases for children in Philadelphia doubled between 1981 and 1982, as did the number of abandonment cases. Even in Dallas, requests for short-term emergency shelter have risen.

Perversely, however, funding for many of the federal programs which address these problems as well as provide other vital services for the young, the poor and the elderly have been slashed. For example, until the recent passage of H.R. 1718, Title XX, which is the major source of federal funds for a wide variety of social services, was operating at a level that was 21 percent below the FY 81 level. Child welfare services were cut 4 percent in FY 82 despite the additional protective and reunification services required by the Child Welfare and Adoption Assistance Act of 1980 and subsequent increases in cases. The Mental Health Block grant is operating at more than 26 percent below the FY 81 level for the individual programs that now make up the block grant. And despite some increases, Head Start has been hurt by cuts in Title XX funds and the CETA program in addition to the withdrawal of state financed services in some places.

Even though the states have tried to shift money and fill in gaps, services and staff have been cut, especially because of the Title XX reductions. In Illinois all 143 social workers assigned to public assistance recipients have been eliminated although child welfare and protective services have been protected. The state is attempting to use caseworkers under the WIN demo to pick up some of the slack. Michigan eliminated 800 positions in 1982. Kentucky cancelled 49 contracts after the FY 82 funding reduction. Homemaker services and transportation assistance were all but eliminated, and the state's only facility for treating emotionally disturbed juveniles in Louisville was shut down. These cuts were particularly hard on children and the elderly. Despite a 50 percent increase in protective service cases in Philadelphia, there are 20 fewer workers. Homemaker services in Connecticut appear to have been curtailed. According to our members in Manchester, Connecticut there they have lost three out of eleven positions, and the professionals must do much more of the clerical work. Waiting lists for Head Start services are increasing; classroom sizes are increasing; and many programs have had to cut their hours. To make matters worse, staff training for all of these programs is being drastically curtailed. This can only mean a serious deterioration in the quality of the services provided.

With further worsening of the states' fiscal condition likely, it is reasonable to expect that the states will find it even more difficult to fill in the gaps caused by the cuts of the last few years. And, except for Head Start, the Administration's FY 84 budget proposals offer no relief. In fact, in some cases, such as the proposal to cap foster care and block grant Community Services with Title XX, the Administration's proposals would withdraw additional funds and shift even greater burdens onto the states.

The health care picture can only be described as a disaster. An estimated 16-20 million individuals who have lost their health insurance as a result of unemployment have joined approximately 25 million people who never had health insurance. The uninsured are showing up at public hospitals in record numbers, putting enormous strain on these already fiscally hard-pressed facilities. In Michigan the number of unreimbursed charity cases rose 29 percent in 1982 at the same time the state Health Department lost $24.4 million in federal, state and other revenue. In Wayne County, 60 percent of the hospitals' inpatients are uninsured as are 40 percent of its outpatients. Here in the District, 5,038 more people resorted to D.C. General's emergency room and outpatient clinics in 1981 than in 1980.

Our members who work in urban public hospitals observe on a daily basis the increased numbers of uninsured and their health problems. A labor and delivery area clerk at Atlanta's Grady

Memorial Hospital told us that 35 of the 40 women she admits daily are uninsured and that, at least once a day, a woman reports receiving no prenatal care because she couldn't afford it. A medical social worker at the Milwaukee County Medical Complex cited complications related to diabetes and high blood pressure as particularly common among the unemployed. A Wayne County General billing clerk has her own indicator for judging the effect of the area's high unemployment -- the number of rejections she gets back from Blue Cross/Blue Shield because the insurance has expired.

The pressure to provide unreimbursed or reduced rate care is exacerbating a disturbing trend that began even before the onset of the current recession -- the closure of public hospitals and the resulting privatization of health care. AFSCME represents workers at two public hospitals facing immediate closure... Jersey City Medical Center and St. Louis City Hospital No. 1. We just learned several weeks ago that the St. Louis Hospital -- the city's only public hospital -- definitely will be shut down. A new private non-profit hospital will be built with some federal assistance. The city could find no assistance is available to build a new public facility.

The implications of this trend are very serious since public hospitals must provide health care to all indigent patients. A federal program of health care for the unemployed and direct aid to public hospitals is desperately needed. In the absence of such a program, adequate funding of existing federal health care programs, which can alleviate the pressure on the public hospitals, is essential.

Privatization is nothing new in mental health and retardation either. For at least 20 years the patient population in state institutions for the mentally ill and developmentally disabled has been dropping. AFSCME represents the employees in many of these institutions, and we have concluded that the decline in patient populations and hospital closures are caused as much by fiscal pressures on the states as by health policy considerations. Deinstitutionalization may have placed many people in the community but, as the recent concern about the homeless has revealed, many of the mentally ill are receiving little if any care. Despite this fact, additional closures are planned as the attached list indicates. Here in Washington, the Administration's plans to reduce federal support for St. Elizabeths in the short run and transfer the hospital to the District in the long run, may, we fear, unltimately jeopardize even this hospital, which has been a center for mental health training and research.

For almost a decade now, we have been attempting to deal with the consequences of deinstitutionalization on the employees and patients of the institutions. With varying degrees of success we have been able to incorporate into federal legislation promoting deinstitutionalization provisions designed to help the employees of institutions scheduled to close find reemployment. In the process, we developed model agreements in Rhode Island and New York in which those states committed themselves to creating state-run community facilities and retraining to prepare institutional employees for work in the community facilities. This approach has the advantage of providing continuity of care for the patients and continuity of employment for many employees, who otherwise would become unemployed. It offers institutional and community-based care within the same system instead of fragmentation between the public and private sector. Despite the fact that the Administrators in both New York and Rhode Island appear very satisfied with the result, our current efforts to develop a similar agreement in Wisconsin are seriously jeopardized by the strenuous opposition of the private non-profit providers.

What little assistance might be available through federal law unfortunately is being seriously undermined. HHS has recently issued regulations for the Developmentally Disabled (DD) program which appear to contradict legislative intent and undercut the effectiveness of the Act's employee protections which we have used to try to get the states to discuss these delivery system issues with us. While the Mental Health block grant no longer contains similar provisions, it does contain authority to use three percent of the funds under the Act for retraining. However, the Secretary had not used his authority. Since no change in this policy is likely, we have begun looking at the new displaced workers program as a source of funds. Our union in New York is actively exploring this possibility. We hope we can work with you to convince HHS to bring its DD regulations more into line with Congressional intent, to make critically needed retraining funds available in this area and to develop more support for state-run community programs.

For the first time in two years, the Congress has shown some willingness to begin to reverse the course of the last two years. We urge you to continue that action by restoring additional funds for the programs within your jurisdiction in FY '84. Among our recommendations to you are:

1. Restoring approximately 3,300 staff to the Employment Service for a total appropriation of $971.2 million.
2. $365 million to bring WIN back up to its FY 81 level.
3. Converting 9,100 temporary unemployment insurance positions to permanent status at an additional cost of $106 million, or a 5.6 percent increase.
4. Building on the Title XX increase in H.R. 1718 to provide $2.8 billion.
5. Increasing Child Welfare Services to $266 million.
6. $1,058 for Head Start, excluding the child care food program.
7. Preserving training funds for Child Welfare Services and Head Start.
8. $483 million for Maternal and Child Health, $98.5 million for Preventive Health Services and $354.4 million for Primary Care, as authorized in legislation now moving through the House Energy and Commerce Committee.

These proposed increases are modest, indeed, in comparison with previous levels of federal support and the immense demands for help. We hope you agree with us that we must begin to close the human services gap and look forward to working with you to begin to rebuild public services.

Actual and Pending Closures of Mental Health and Retardation Facilities Since 1981

Year	State	Facility	Type	Location	Units Closed	Layoffs
A. Previous Closures						
1982	MN	Rochester SH	MH/MR	Rochester	all	353
1982	MI	Hillcrest Ctr.	MR	Howell	all	244
1982	MI	Alpine Ctr.	MR	Gaylord	all	192
1982	IL	Adler MHC	MH	Champaign	all	115
1982	IL	Bowen DC	MR	Harrisburg	all	258
1982	FL	South Fla. SH	MH	Hollywood	forensic	327
B. Scheduled Closures						
1983	FL	Tallahassee Sunland	MR	Tallahassee	all	358
1983	MI	Plymoth Ctr.	MR	Northville	all	450
1984	FL	Orlando Sunland	MR	Orlando	all	842
1984	IL	Dixon DC	MR	Dixon	all (except 3)	1,072
C. Proposed Closures						
N/A	NJ	Trenton Psych H	MH	Trenton	several	250
N/A	MO	Farmington SH	MH	Farmington	all	-
N/A	IA	Clarinda MHI	MH	Clarinda	some	-
N/A	MN	(not specified)	-	-	some	-
N/A	NY	Craig DC	MR	Sonyea	most	est. 375
N/A	NY	Marcy SH	MH	Utica	all	-
N/A	NY	Gowanda	MH	Buffalo	all	-
N/A	AZ	ATPCoolidge	MR	Coolidge	all	-
N/A	FL	Ft. Myers Sunland	MR	Ft. Myers	all	-

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NEW YORK AND RHODE ISLAND LEAD THE WAY—DEINSTITUTIONALIZATION A NEW PARTNERSHIP

(By Martin D. Hanlon)

Over the past several years, there has been a radical change in the care of the mentally retarded. Throughout the United States, tens of thousands of retarded people have been released from state institutions and placed in community residence settings. Deinstitutionalization, as this policy has come to be known, was a reaction to the overcrowded and untherapeutic conditions once characteristic of almost all state facilities for the mentally retarded and for the mentally ill as well. Professional opinion held that life in a small community residence offered far greater opportunities for physical well-being and personal growth than large institutions.

Now, many advocates of deinstitutionalization have serious reservations about the implementation, if not the ultimate objectives, of this policy. Responsibility for the care of the retarded is often turned over to private agencies that lack the resources to sponsor or provide humane, therapeutic care. A "community residence" sometimes means an overcrowded facility which houses one hundred or more clients in institutional-like conditions. Staff members are generally underpaid, work under difficult conditions, and often have little experience or specialized training. Few are unionized. Not surprisingly, turnover rates of direct care staff members within proprietary and voluntary agencies for the retarded often exceeds fifty percent each year.

Many parents' organizations and other advocacy groups for the retarded have begun to reevaluate the relative advantages of public and private care. State institutions are now better staffed, physically more attractive, and provide much better care than a decade ago. Some parents have demanded that state mental retardation officials modify the policy of transferring retarded clients from institutions to private residential care facilities. One concern is: "If the agency goes out of business, what happens to my child?"

Most states, however, continue along the path of deinstitutionalization. Court-mandated consent decrees often require the states to enforce specific timetables for institutional reductions. In the significant case involving the Pennhurst Center for the Retarded outside of Philadelphia, U.S. District Court Judge Raymond J. Broderick ruled that the institution should be closed and its more than one thousand residents should be transferred to small, community based facilities. The 1978 decision led to a major controversy within professional and legal circles over the practical effects of shutting down a huge facility in the absence of an established network of private residential homes. The late David Balla, an associate professor of psychology at Yale and a noted authority on the care of the mentally retarded, made a detailed investigation of conditions at Pennhurst in late 1979 at the request of the American Federation of State, County and Municipal Employees, which opposed the closure ruling. Balla supported the union's position and noted that: "There is a need for a congregate care facility, such as Pennhurst, as part of the total spectrum of services for retarded citizens." Subsequently, the federal courts have revised the terms of the original District Court ruling and Pennhurst remains open.

But the weight of professional evidence, which has shifted away from the policy of rapid institutional closures in the absence of viable community care, has made little impact in many states. The main reason is money. Contracting out for residential care of the retarded is often cheaper than maintaining state institutions. This has become especially so given the enormous costs of meeting federal requirements for

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facility and staff upgrading that are necessary to secure Medicaid reimbursement. The result is a strong temptation to cut state-run services regardless of the consequences for long-term retarded clients. A related issue is the fate of institutional employees. Closing institutions inevitably means the loss of jobs. Apart from the considerable economic and personal costs of unemployment to laid off employees, the states lose a wealth of experience and the huge investment in staff training that has been made in the decade since the Willowbrook case began. From a purely cost-benefit perspective, the price of unemployment benefits, lowered employee morale, and service declines that accompany layoffs can outweigh the savings from personnel reductions.

A New Alternative

A few states have approached the issue of long-term public responsibility for the retarded in a more creative and promising way. This article describes retardation policy in two states, New York and Rhode Island. In both, mental retardation program directors and the unions which represent state institutional employees have formed partnerships to implement an alternative to the usual path from institutional to private, community based care. In essence, the strategy involves the gradual reduction in the resident populations of large institutions coupled with the establishment of networks of state-run community residences, many with ten or fewer beds. In turn, these "community living arrangements" (CLAs) are staffed by institutional employees whose jobs would otherwise be eliminated due to the decline in institutionalized client populations. The key element is a joint union-management structure for recruiting employees for community residence work and providing them with the training needed to carry out job responsibilities in the radically different context of a small group home.

This new policy of maintaining state involvement in the care of the retarded in the context of deinstitutionalization has several important advantages. For the union (CSEA in New York and AFSCME Local 1293 in Rhode Island), the immediate benefit is job security for its members. For state retardation officials, the policy offers a means of simultaneously dealing with several difficult issues: compliance with consent decrees, closing institutional wards that have become prohibitively expensive to operate under new, higher standards, insuring adequate care for retarded clients, and satisfying the demands of unions and their legislative allies. And increasingly, there is evidence that community based care in state-run facilities can be a cost-effective alternative to institutional care.

Like any new policy, however, difficulties in practice may outweigh the logical advantages of a program. State retardation departments have little experience in running community based group homes. Employees who have spent years working in an isolated institutional setting may not be able to adjust to a community treatment setting. Any new effort is inevitably going to have to go through a "shake down" period and the political costs of an early failure may doom the program. And like any bureaucracy, a state retardation department may find that it's simply easier to continue on a familiar policy course despite accumulating evidence that it may ultimately have to be changed. New York and Rhode Island, along with their public employee unions, decided that the old policy was no longer acceptable.

New York: Deinstitutionalization and Continuity of Employment

In 1976, the state of New York signed a consent order that represented the culmination of four years of stormy litigation over the fate of clients at the Willowbrook State School. The order, which has since undergone some modification, mandated sweeping changes in the size, function, and character of the institution. At its peak, Willowbrook —since renamed the Staten Island Developmental Center (S.I.D.C.)—housed over 5,000 retarded people under conditions that were by common admission, intolerable. Within the framework of the consent order, the State has committed substantial resources to improving the staffing and physical environment of the facility. Each client now receives several hours of treatment and habilitation services provided both on site and in the community. Staff at the S.I.D.C. have benefited from a massive ongoing training program that has been a key element in changing the institution from a custodial facility to one which prepares clients for a brighter and more independent life in the community. The continued exodus of clients to community based settings and smaller, borough-wide developmental centers has brought the Staten Island facility's resident population down to the current level of 1,200. Further reductions mandated by the consent order will bring the eventual population down to 250.

As in many other states, the impact of a consent judgment imposed on a single facility also meant changes for the statewide mental retardation system. New York's system is the country's largest, with 20 regional and borough-level developmental centers throughout the state. In 1979, there were 18,000 retarded clients living in state-run institutions. Since then, the institutional population has been reduced to approximately 12,000 while 6,000 clients have been transferred to community settings.

The reduction in the size of these institutions has implications for the job security of institutional employees. The long-term population projections outlined in New York State's Office of Mental Retardation and Developmental Disabilities 1979-1984 Five Year Plan mean an inevitable decline in the demand for institutional employees, despite notable increases in the ratio of staff members to clients over the past several years. In New York as elsewhere, moving clients to community settings has generally meant the transfer of daily responsibility for client care from the state to private voluntary and proprietary agencies.

But there is an important difference. New York State retardation officials and union leaders rejected an exclusive private care solution. Instead, the state has created a network of state-run community residences staffed by transferred institutional employees.

Training for Community Based Employment

At the heart of New York State's initiative is a massive training effort to prepare transferred institutional employees for jobs in community day program and residential settings. Since the Willowbrook decision, the state has invested millions of dollars in upgrading the skills of institutional employees. Much of the training has been directed at non-professional direct care employees, who, in New York, carry the title of mental retardation therapy aides, or MHTA's. The typical therapy aide who remains through the initial one year probationary period is far better equipped to carry out the numerous tasks related to preparing clients for eventual placement in the community than his or her counterpart five years ago. In keeping with the guidelines of the consent judgment, direct care staff are instructed in how to carry out client habilitation plans that are prepared for each client by program planning teams.

Despite this training input, however, employees who are being transferred from an institutional setting to a community residence setting have additional training needs. The issue is summed up by OMRDD Director of Staff Development and Training, John J. Keegan:

> The movement to the community led us to ask what preparation was needed for staff to carry out their jobs. Now, all Developmental Center staff moving to community sites are trained to carry out their responsibilities in that setting. But the feeling was that when an employee went out into the community, there would be a lot of new areas he or she would have to deal with.
>
> First of all, the employees have got to think about themselves and their new environment. They are going into a changed situation—from a self-contained world at a Developmental Center where meals, doctors, dentists and other professional resources are right there—to a community residence, where staff are encouraged to use existing community resources—everything from

medical services to recreation facilities. Working life is obviously going to be much different. Therefore, our task is to develop training that answers to these emergent needs and satisfies existing regulations.

OMRDD's Continuity of Employment Training Programs began in 1979 when the State, set up its own community residence system. Before then, all community based services were run by non-State agencies, such as Catholic Charities or United Cerebral Palsy of New York. Altogether, there were about 700 privately sponsored units for the mentally retarded in New York State. In the first year, 1979-80, OMRDD set up 35 state-run community residences; presently, there are at least 215 residences. The numbers are scheduled to increase over the next several years although budget limitations and community opposition to residential homes for the mentally retarded have slowed the trend somewhat.

The Continuity of Employment Training Program is sponsored jointly by OMRDD, the Civil Service Employees Association, and the Governor's Office of Employee Relations. Funds to run the program have been provided by the Committee on the Work Environment and Productivity (CWEP) along with matching federal funds. It is by far the largest department-wide joint union-management program of its kind in the United States. In line with its overall goal of training direct care and supervisory staff for community based employment, the Program has carried out extensive curriculum research and development as well as extensive training, and has created a complex information system to monitor and evaluate the progress of the program.

The training process is linked to the budget cycle. Planning begins when officials at each developmental center find out how many community facilities are budgeted for opening within the coming year. There are actually two categories of facilities based on the level of core needed: community residences and Intermediate Care Facilities (ICF/MR). Once the available funds are known, developmental center staff determine the actual number of employees who will require training.

At least four weeks prior to the opening of a community home, the Director of Personnel and the Director of the Developmental Center begin to identify the employees who are to receive training. In keeping with Civil Service regulations, the facility must post for these positions. In all cases, the transfer to a community residence setting is on a voluntary basis. Once an employee has requested transfer, however, he or she is then required to go through training. The actual training curriculum was developed by OMRDD's Bureau of Staff Development and Training, although Keegan emphasizes that each developmental center is encouraged to create its own material to address particular site level needs. Training materi[illegible] The focus is on the concrete day to day aspects of working within a community setting. One videotape describes the mechanics of taking a public bus ride with clients with cerebral palsy; another portrays shopping with clients at a local market. "We wanted to make the training materials experiential and informative," Keegan notes, "in order to show employees what it would be like working in a new setting and the new skills needed."

Each staff member receives approximately 150 to 200 hours of training which is provided through work release time. The location is kept as flexible as possible; employees who have not yet transferred are given instruction at the developmental center while region-wide training sessions are held for community residence employees. In some cases, training has taken place in the living room of a community residence and at various hours to accomodate shifts.

At the present time, almost all employees who are currently working in a community residence have received training. For every employee, the Bureau of Staff Development and Training maintains a comprehensive training record which includes the employee's work location and the number of training modules completed this detailed information is important to plan followup training and to maintain federal certification. This information system is now being computerized. The next phase involves competency based testing which will use the

"The Morgado Memorandum"

The executive basis of New York State's policy was contained in a memorandum issued on June 15, 1978 by Robert J. Morgado, Secretary to Governor Carey, to the Commissioners of Mental Health (OMH) and the Office of Mental Retardation and Developmental Disabilities (OMRDD), and to the Division of the Budget. The memorandum outlined several policy goals:

- Continue to improve the staff to client ratio in all of the state's developmental centers. The specific target ratio was set at a minimum of 1.78 staff members for every client.
- Maintain parity between day treatment and community residential programs operated by private providers under contract to the state and programs directly operated by OMRDD.
- Continue to develop small community residential facilities as a primary alternative to institutional care. The average level of disability of clients in state facilities would be kept similar to that of clients in private care.
- Insure that no person is released from a state institution unless adequate community services are available. Also, no eligible person should be denied access to an institution if appropriate residential alternatives are not available in the community.
- Provide the necessary employee training, retraining and job series options to realize these objectives and to invite the assistance of employee representatives (i.e., unions). Special attention should be given to the development of community oriented job series that build on the skills and experience of the existing institutional workforce.
- Provide clients who are discharged to community settings and who need intensive client care or skilled nursing care with the requisite care identified in the Willowbrook Consent Judgment.
- Provide alternative employment opportunities for employees who are not required to meet the policy goals and standards established for institutional and community support programs. The first option would be an alternative job within OMRDD. If this is not feasible, an employee would then be considered for employment in another state agency and would maintain full collective bargaining rights. Moreover, the job possibility would not entail a significant worsening of the conditions of employment, i.e., lower pay, increased safety hazards, lower rank or status, or an unreasonable commuting distance.

The Morgado Memorandum was not intended as a guarantee of job security; in the face of fiscal and legislative constraints, no such guarantee can be offered in state employment. But it did provide a clear statement concerning the state's commitment to integrate the needs of the Union and its members (e.g., job security, preservation of job-related benefits, and additional training) with the state's overall policy directions in mental retardation and mental health.

content of the standard curriculum materials but will make them more self-instructional. The objective is to build additional flexibility into a system that comprises three shifts of employees scattered over hundreds of work locations.

Altogether, over 1,236 former institutional employees have transferred to community settings and have completed related training.

Throughout each phase of the training initiative, there has been a close, collaborative relationship between CSEA and OMRDD. For the union, a collaborative policy entails some degree of risk taking. A union local president, for example, may face opposition from members who fear that cooperating in a deinstitutionalization plan will lead to the elimination of their jobs. Given AFSCME's critical position on deinstitutionalization (though not in the case of Rhode Island and New York) there is likely to be some degree of suspicion among members. In New York, many local presidents were initially wary of the transferred retraining program. But mistrust has largely given way to active cooperation as it has become apparent that: (1) the trend toward community based treatment is not likely to be reversed, (2) the state has given a firm public commitment to the protection of the job rights of individual employees, and (3) community based care offers opportunities for real improvements in the career patterns and quality of working life of union members. This cooperative attitude between CSEA and OMRDD is the foundation of the most recent training program for transferred employees.

Labor-Management Consortium Training Program

Most mentally retarded clients who are classified as either mildly or moderately retarded are no longer living in public residential institutions. Many of those who remain in institutions, including substantial numbers of clients who are being prepared for community placement, are classified as severely or profoundly disabled. In turn, a substantial portion of this population is multiply handicapped; that is, many are clients who are blind, deaf, or unable to walk in addition to being retarded.

Providing residential and treatment services to a multiply disabled population places special demands on direct care staff members and their supervisors. As multiply handicapped clients have been transferred to community residential settings, the need for staff training in dealing with the complex problems of this population became more apparent. There is a shortage of professional clinical personnel, particularly physical and occupational therapists available to all shifts, in public residential facilities.

The challenge of providing quality care to multiply handicapped clients dispensed throughout a broad network of community residence homes is the focus of a unique training program cosponsored by OMRDD, CSEA, and the Governor's Office of Employee Relations. The program is partially funded by a $224,000 Grant of National Significance from the Federal Administration on Developmental Disabilities, one of only two grants of its kind awarded nationally. Additional funds are provided by the project sponsors: OMRDD contributed $39,000 and the OER/CSEA Joint Committee on the Work Environment and Productivity has contributed a grant of $140,000. The training funds support a one year training program for 240 direct care employees and 60 supervisors who have volunteered to work with multiply handicapped clients in community residence settings. As outlined by Project Director Mary Anne Delaney, the training program covers eight different skill areas:

- An introduction to sensory disabilities, including the special developmental needs of blind and deaf retarded clients.
- Daily living for retarded clients, including bathing, dressing, and meal preparation.
- The use of adaptive equipment. Employees will be trained in the use of braces, wheelchairs, and the other types of special equipment required by multiply handicapped clients.
- The techniques of therapeutic feeding. Many institutionalized clients have been limited to pureed food. In the interest of promoting normalization, direct care staff in community residences will be involved in teaching

clients how to handle a more complex diet. Clients will learn the basic skills of biting, chewing, and swallowing.

- Communication skills. Employees will be trained to assist handicapped clients to more effectively communicate with others. For example, a deaf client with one arm would be taught a modified form of sign language.
- An introduction to the physical causes of disability.
- Basic therapeutic activities, including exercises for improving client's range of motion.
- Recreation and leisure activities.

According to Delaney:

> We want to develop specific skills that will enable employees to become more closely involved with the clients. As you become more skilled, you begin to discover more about the clients' personalities regardless of their degree of disability.

Reports about the training program created some concern within the professional associations representing licensed therapists. Delaney and CSEA's Program Specialist Dr. Paula Lambert met with the associations and clarified the scope and intent of the training. In Delaney's words:

> We are teaching aides the language and some of the specific skills so that they can carry out program plans developed for clients. The training will actually extend the effectiveness of licensed occupational and physical therapists by making it possible to develop plans for more people. Once this was said, we had no problems with these groups.

The initial one year pilot program is being carried out in five of the state's developmental centers: Craig, Staten Island, Letchworth, West Seneca and Suffolk. The sites were chosen on the basis of geographical distribution and suitability for replication. At each site, a professional level staff person has been hired to coordinate the training program. The coordinator reports to Ms. Delaney but is placed within the Department of Education and Training at each developmental center.

Training sessions began last July. Initially, trainees received six hours of classroom teaching a week along with independent study requirements. They visited community residences and day programs. Beginning in September, classroom teaching was reduced to three hours a week and combined with six hours of supervised practice in specific skills carried out at community residences. Altogether, employees will receive 400 hours of training over a nine month period.

The skill training disabilities program, like the general community residence training program, has been a joint union-management project from the beginning. John Keegan of OMRDD and Paula Lambert of CSEA authored the project funding proposal. Keegan, Lambert, and Thomas Hines of the Governor's Office of Employee Relations make up the Project Management Committee—the executive body of the training program. There is a similar organizational structure within each of the five developmental centers; it consists of an administrator, a staff member from the education and training department, and the CSEA local president or designate. This local project management team meets weekly and advises the site level coordinator. In Delaney's view, local union presidents have been:

> . . . extremely supportive of the project. They see it as a way of getting better training for their constituency. The union is also excited that we're working with staff from the Regent's External Degree Program to obtain college credits for the courses.

CSEA is also encouraged by the possibility of career upgrading. The Project Management Committee is supporting an effort by OMRDD seeking a new job description for employees who complete the training program: Community Residence Aide II (ICF). This would be a Civil Service Grade 10 position that would fall between the existing direct care title, Community Residence Aide I (Grade 9), and the position of Assistant Director of a Community Residence (Grade 11). The new title would be limited to the 240 direct care trainees who are now in the program and future employees to be trained over the next several years. The target goal is to train 300 MHTAS employees in new skills to work with the multiply handicapped.

The program is intended to be one of several training components within OMRDD's long-range plans for transferring institutionalized severe and profoundly retarded clients to state-run community residences. The program's status as a Grant of National Significance portends that New York's experience will provide the model for similar efforts in other states. One of its innovative components is a national reactor panel organized by the National Association of State Mental Retardation Program Directors, and composed of AFSCME leaders and retardation officials from several states. The panel will evaluate the program and assist in the diffusion of results to union and state policy makers throughout the country.

Rhode Island: The Ladd Center Program

The Ladd Center is Rhode Island's major institution for the retarded. Less than four years ago, Ladd Center housed 750 residents and employed over 1,000 staff. As in many similar situations around the United States, Ladd officials were the defendants in a court suit alleging poor treatment of residential clients—a suit which ultimately led to a consent order and plans for the eventual transfer of most of the client population to community residence settings. The Rhode Island Department of Mental Health, Retardation, and Hospitals (DMHRA) had prior contracts with private retardation agencies, but in the view of Dr. Robert Carl, Jr., Associate Director of Rhode Island DMHRH and the state's highest retardation administrator, these agencies were "woefully ill-prepared to cope with the idiosyncracies of long-term institutionalized clients." According to Carl:

> . . . too many of our (private) providers were unwilling to change. They kept demanding a better class of clientele, often refusing to serve persons with behavior problems or multiple handicaps. Some providers claimed they merely needed more money to serve such clients, but offers of more money and higher rates merely generated some new excuses. Meanwhile, people languished.

Rhode Island officials also felt that staff continuity was an important factor in preparing retarded clients for a normal life in the community. The changeover from state care to private care might create tension and uncertainties that would work against successful client placement. Employee morale was critical; few could be expected to give full attention to clients when the end result of a successful communitization program was the elimination of one's job.

The State's misgivings about transferring responsibility for the retarded to the private agencies and its basic faith in the competence of its own workforce led to an historic agreement. On April 30, 1980, the Division of Retardation and Rhode Island Council 94 of AFSCME, on behalf of Local 1293 of the Ladd Center, signed a memorandum of understanding which laid out the conditions for employee reductions at the institution and the staffing of state operated community residences by Ladd employees. The memorandum pledged joint union-management support for the policy of deinstitutionalization with the proviso that "no Ladd Center employee will be terminated, reduced in pay or class, nor laid off due to deinstitutionalization plans." Necessary employee reductions at Ladd would come about through normal attrition and transfers to community based homes. Moreover, transferred employees would continue to enjoy full collective bargaining rights including pensions, seniority, vacation benefits, and health insurance. The agreement also called for the retraining of Ladd Center staff in skills appropriate for community work. In short, the state and the union negotiated a no layoff guarantee conditional upon employee and union willingness to accept transfer to residential homes following the necessary retraining.

One notable aspect of the Ladd program has been the careful planning that has gone in to each phase of development. Before the first clients were transferred, the Division of Retardation commissioned attitude surveys to assess the willingness of institutional staff to move into community settings. One survey, carried out by a University of Rhode Island research center, found that many employees were receptive to transfer, but only if skill training was provided. The survey also found that the economic factor was important: employees wanted some financial incentive for moving to a community facility. This did not necessarily mean more pay, however. A reduction in commuting costs would suffice for many. Another key finding was that most employees had little appreciation of the nature of work life in a community home. The survey report recommended that employees be given more information about community programs and that prospective volunteers should be given a chance to work in a small group home before making a commitment to transfer.

The next phase was the design and implementation of a training program, or "community preparation program" as it is called by staff. Training funds were obtained through the Comprehensive Employment and Training Act (CETA). Skill areas to be covered in the program were jointly formulated by union representatives and officials from the Division of Retardation. Rhode Island College received the contract for developing the specific curriculum around these skill areas. The training curriculum approximated a college course and trainees received college credit upon completion. Included are sections on the nature of mental retardation and other developmental disabilities, how to develop a daily routine for residents, the use of leisure time, medication, illness prevention, and a number of skills that are specific to community residence work including financial record keeping, life safety procedures, and how to deal with neighbors.

The Division of Retardation and AFSCME formed a private, not-for-profit corporation, AFSCME Career Development in Rhode Island, Inc., as a vehicle for training sponsorship. The entity was also intended as a means of insuring that the State Budget Office would not assume control of Federal training funds. Dr. Carl is the corporation's president.

Union Involvement

Jerry Clancy, former AFSCME Local 1293 Vice President, stated the union's position this way:

> We went through all the standard arguments against deinstitutionalization, but we felt that we were not opposed to it as long as it could provide a better atmosphere for clients. So, in 1979, when Bob Carl came along and found that both groups were comfortable with one another and they were receptive to what we had to say, the negotiation process got under way. The basic thing was that both sides agreed on the type and level of care we wanted to provide. This basis of understanding about the importance of continuity of care and the need for experienced employees was what made this program work. Out of the 90 clients we've sent to the community, only three have returned. And it's important to keep in mind that our average client has been institutionalized for 30 years.

The program began with the transfer of a group of clients to a small residence on the Ladd campus, a move which was intended to simulate community living and provide staff with the opportunity to work out conceptual and practical problems. Later, the program moved to a house in Narragansett on the Atlantic coast. This was used as a "staging area" for three months in preparation for the actual move to a community residence. Once the program was in operation, staff members and their clients were often transferred together. In the words of former AFSCME Local 1293 President John Vars:

> When a particular client is to go out to a group home, there is often an attachment between him or her and a particular institutional attendant. In some cases, their relationship goes back ten or twenty years. The attendant will say to us: 'If my client is going to a group home, then I'm going to transfer there—we're not going to separate: if he goes, I go too.' And that kind of attitude is important for continuity of care.

Within the terms of the union-management memorandum of understanding, transfer to a group home is not a one-way ticket: employees retain the right to return to the institution. Few have done so. Most feel that working conditions and opportunities for helping clients are better in a group home than in the institution. According to Clancy:

> You can do so much more for clients when they are working with four clients rather than with 45. Here at Ladd, if you want to take clients to a movie, you've got to load them into two buses—it's a big deal. Out in the community, you hop in the van and go.

One potential problem is that because work in a community setting involves different tasks than institutional work, existing job descriptions may not adequately encompass the employee's range of duties. "Out of title" work can become a serious labor relations issue. Local 1293's approach is to be pragmatic and allow some degree of flexibility. "We voluntarily work out of specification," as one union official noted,

> . . . and that includes cleaning ovens and washing floors. But it's important to understand that we structured what this program would look like. We said that our members wanted CPR training, dietary information, and so forth. For some of the guys who've never cooked, we had a basic cooking class. So, the point is, you're working out of specification but you are learning new skills that you wanted. You're also getting the satisfacation of seeing someone who has been institutionalized for years turn into a person who is active, cares for himself, and can relate to others.

Local 1293 is applying for an upgrading of job classifications and hopes to achieve salary increases that reflect increases in skills and job responsibilities.

How do labor and management assess the results of the Ladd Center Program? AFSCME's opinion is very positive. Union officials note that the transfer of clients to community settings has reduced overcrowding and improved working conditions at Ladd. Labor-management relations have also taken a turn for the better. Employees are no longer fearful about their job security and have a strong commitment to the success of the communitization program. And as indicated, employees who have transferred to community houses are satisfied with the change. Many cite the opportunity to work more intensively with their clients on an individual basis; "I have the satisfaction of seeing my clients achieve things I would never expect to see in the institutuion," is an often repeated comment.

Another indicator of employee satisfaction has been a significant reduction in the use of sick time—by 80 percent in one evaluation. According to Jerry Clancy:

> People want to come to work. It's not the pressure type of situation: you don't see the burnout that is typical for a large institution. They come to work on time because it's important not to cause problems for your co-workers.
>
> This new attitude comes out in grievances. You still have them, but they tend to be over procedural matters. You just don't see problems arising from employees not coming to work.

Ladd Center Director George Gunther, a principal architect of the communitization program, agrees with Clancy:

> It makes things easier for management. When you have two people coming on the evening shift at four and two people waiting to leave, if one of the second shift people doesn't show or call in, believe me, it's not a *management* problem. Whoever has to stay on duty until the late man comes is going to straighten him out. It's not like in a big institution where people can say: 'We'll get by until he gets here.'

The program has been a remarkable success from the perspective of state officials. Over the past three years, the client population at Ladd has been reduced from 750 to less than 500. (Ultimately, the population will decline to 100 residents.) The institution's budget has been reduced from $21 million to $16.8 million and all savings have been transferred to community programs. The number of clients served by day programs has climbed from 800 to over 3,000 in three years. More than 50 group homes have been established throughout the state. Overall, over 300 formerly institutionalized clients and over 300 employees have moved to community based homes. As in New York, union-management cooperation has created an environment which promotes the interests and well-being of both clients and employees.

STATEMENT OF RICHARD E. VODRA, PRESIDENT, COALITION FOR HEALTH FUNDING

Senator WEICKER. The next witness is Richard Vodra, president of the Coalition for Health Funding.

Mr. Vodra.

Mr. VODRA. Mr. Chairman, I'm Richard Vodra, president of the Coalition for Health Funding. On behalf of the more than 50 health and health-related organizations which comprise the coalition, I thank you for the opportunity to appear before you this morning and to lead off the public testimony on behalf of the Department of Health and Human Services.

The Coalition for Health Funding firmly believes that the Federal commitment to discretionary health programs is essential to the health and well-being of our citizens.

Ever since the first Congress in 1790, the Federal Government has acted to protect the health of those under its jurisdiction. It has always stepped in when necessary to guarantee the purity of food and drugs, to promote the search for knowledge about disease, to control infectious illness, to educate health professionals, to develop better health care facilities, and to provide general health care and special services.

The programs that accomplish these and related goals today are operated by the various components of the Public Health Service within the Department of Health and Human Services.

Dollar for dollar PHS programs have a greater positive impact on the health of our citizens than any other spending in our health system. This is because PHS programs largely involve investment, investment in ideas, in people, in new health care delivery systems, in health promotion and disease prevention and in general support for the whole health care network.

As you can see by the chart on the cover of our statement the effective level of PHS funding has declined steadily since 1978. The actions of Congress for the fiscal year 1983 budget led by this subcommittee markedly slowed the decline, expressing your belief that these important programs have been cut enough.

Yet President Reagan requested a reduction of $95 million in his budget from the original fiscal year 1983 levels. The citizens who benefit from these vital programs cannot afford such a cut. In fact. the cut is even greater than appears on our chart because these 1983 levels shown have not been adjusted for the supplemental funds recently provided by this subcommittee in the jobs bill.

When these are taken into account, the President's budget falls $240 million short of current funding levels before any inflation adjustment is made.

The graphs included at the end of our testimony show starkly just where our commitment to discretionary health funding is headed, program by program.

The Coalition for Health Funding believes these trends—particularly in the President's budget—represent a mistaken idea about health policy.

The health of Americans requires more than just a good system of providers and facilities. Many essential activities absolutely cannot be provided by the private sector on an individual basis, and the cost of not funding these programs now will be increased Federal outlays in the future for medical care.

These essential activities are not expensive, especially in the context of total spending on health care. In 1984 less than 2 percent of that total will go to PHS programs.

That 2 percent has to fund health education and training, research, disease prevention, quality control, and a wide range of special services.

We urge this subcommittee to restore the $95 million in funds that the President would cut and provide sufficient moneys to allow the discretionary health programs to provide at least the same level of services in fiscal year 1984 as they currently have in fiscal year 1983.

We commend you, Senator Weicker, and your colleague Senator Hatfield and the other Senators who have joined with you for your alternative budget proposal that proposes major increases in the health area.

Mr. Chairman, limited time available does not permit me to discuss the budget in detail. We have done this in our book, an analysis of the Federal Public Health Service budget, fiscal year 1984, which your staff has, which we'd appreciate the opportunity to put in the record if we could.

Senator WEICKER. It is directed at this point.

[CLERK'S NOTE.—The book is contained in the subcommittee's files.]

Mr. VODRA. Let me simply touch on several special concerns of our membership. We have watched the shell game at NIH, in which a totally inadequate budget is put forward in the name of research stabilization.

The coalition supports an increase of $412 million over the President's budget to allow NIH to fully fund those grant centers, clinical trials, and other programs it needs and has testified for over the years.

Other areas of special concern include the major cuts in student assistance programs, the health professions, education, the totally inadequate levels for block grants, and the inadequate levels for prevention programs.

Funding charts included at the end of our statement outline our specific recommendations for the Public Health Service.

Thank you for the opportunity to speak before you today.

PREPARED STATEMENT

Senator WEICKER. Mr. Vodra, thank you very much. Counsel tells me that that book is a very fine piece of work and I will take a look at it.

Mr. VODRA. Thank you very much.

[The statement follows:]

STATEMENT OF RICHARD E. VODRA

Mr. Chairman, members of the subcommittee, I am Richard Vodra, president of the Coalition for Health Funding. On behalf of the more than 50 health and health-related organizations which comprise the Coalition I thank you for the opportunity to appear before you this morning.

The Coalition for Health Funding comes to you with a simple message: the federal commitment to discretionary health programs is essential to the health and well being of our citizens. Since the first Congress in 1790, the federal government has acted to protect the health of those under its jurisdiction. It has always been willing to step in, when necessary, to guarantee the purity of food and drugs, to promote the search for knowledge about disease, to control infectious illness, to educate health professionals, to develop better health care facilities and to provide general care or special services.

The programs that accomplish these and related goals are today operated by the various components of the Public Health Services (PHS) within the Department of Health and Human Services (HHS). The Coalition strongly supports the funding for these particularly important activities. Dollar for dollar, PHS programs have a greater positive impact on the health of our citizens than any other spending in our vast health system. This is because PHS programs largely involve investment--investment in ideas, in people, in new health care delivery systems, in health promotion and disease prevention and in general support for the whole health care network.

When programs such as those of the PHS have been so successful and continue to be so important, they should receive high priority attention when resources are allocated in a budget. Yet President Reagan has requested a cut of $95 million in the FY84 PHS budget. Neither these vital programs nor the many Americans they benefit can afford a cut of more than 10 percent in real terms from 1982 and almost 20 percent since 1981. The graphs included in our testimony packet tell more clearly and starkly just where our commitment to discretionary health funding is headed. The Coalition for Health Funding urges Congress to correct these policy mistakes and to continue to make the modest investment necessary to protect our health.

The health of Americans requires more than just a good system of providers and facilities. Many essential activities cannot be provided at all by the private sector or on an individual basis. And, the cost of not funding these programs will be higher increased future outlays for medical care.

These essential activities are not expensive, especially in the context of total US spending on health care. In 1984 our national health expenditures will probably come to $350 billion; less than two percent of which will go to PHS programs. That two percent has to fund health education and training, research, disease prevention and treatment, quality control and a wide range of special services. We urge this subcommittee to restore the $95 million in funds that the President would cut and provide sufficient monies to allow the discretionary health programs to provide at least the same level of services in FY84 as they did in FY83. The Coalition for Health Funding commends the members of this subcommittee who carefully deliberated over last year's budget request from the President and rightly rejected most of the reductions. This year, when even more people are in need of the services and support provided by the PHS and research opportunities await only adequate funding to come to fruition, we urge you to commit adequate funds to these vital programs.

Health Research

Health research has contributed substantially to the well being of our nation's citizens and economy:

- Each dollar invested in research is estimated to have produced $13 in savings from benefits such as reduced incidence of illness and medical costs and increased life expectancy.
- Health research has produced knowledge and discoveries which have led to economically significant commercial developments in a number of areas such as minicomputers and food preservation.
- At this critical juncture in the evolution of our nations's biomedical and behavioral research effort, research opportunities of extraordinary human and economic promise are apparent.

The President's request for the research supported by the National Institutes of Health (NIH) and the Alcohol Drug Abuse and Mental Health Administration (ADAMHA) fails dramatically to support the program growth necessary to maintain our national leadership in research. The Coalition believes that the biomedical and behavioral sciences should be treated at least as generously as other scientific endeavors.

Several years ago the Congress and the Administration agreed to stabilize research programs at minimum levels, and promised that funds sufficient to reach that goal would be provided. Unfortunately, the Administration has made a mockery of this policy, reducing its budget requests to little more than a shell game. For the coming fiscal year, the President proposes--in the name of stabilization--an NIH budget which makes across the board cuts in all grants and reduces indirect cost payments, support for centers and research training. This is inconsistent with the policy you and the Administration agreed upon and the Coalition urges you to fully fund this country's health research efforts.

Health Services

Federally supported health care service programs can provide help to only a fraction of the many Americans who need their assistance. For the millions of elderly, migrant workers and Native Americans who rely on these programs, this is their only source of preventive and theraputic health care.

Under the President's FY84 budgetproposal, however, almost every segment of the services provided to Native Americans will be reduced by cuts in funding for hospitals and health clinics, dental care, mental health and alcoholism treatment, sanitation funding, public health nursing and health education.

The President further proposes reducing aid to programs which have successfully induced students to practice in areas with acknowledged shortages in health care, cutting the pay of health professionals and ending health planning and health maintenance organization funding.

The cuts and too small increases in the Centers for Disease Control program funding proposed by the President would reduce efforts to prevent disease and decrease aid to those already suffering from illnesses. Under his budget we would immunize fewer children than in FY83, eliminate all of the funding for tuberculosis project grants just when the incidence of new cases of tuberculosis is rising, and help fewer sufferers of the epidemic of venereal disease. Neither does this Administration request any funding at all for the highly cost-effective fluoridation program, nor sufficient funding to deal with newly emerging health problems such as acquired immune deficiency syndrome, a collapse of the body's immune system which has an alarmingly high fatality rate.

Health Professionals Education

The President's proposed 32 percent cut would have a disasterous impact on the training of our health professionals. The soundness of the comprehensive and essential student and institutional assistance programs is endangered by the President's proposal to reduce or eliminate the federal commitment to health professions education. We agree with the Administration's stated goals to promote a sufficient supply of primary care practitioners, to encourage health professionals to locate in remote or underserved areas, to encourage minorities to choose careers in the health professions, to improve the utilization and distribution of nurses, to prepare health professionals to serve an increasingly older population and to emphasize health promotion and disease prevention for all patients. And, because we do support these policies, we can neither understand nor support cuts in primary care and family medicine programs, minority school support, the national health service corps or nurse or public health training.

None of these acknowledged important needs will be met without a sufficient continuing commitment to essential student assistance programs such as health professions student loans, nursing student loans, public health traineeships, exceptional financial need scholarships and health education assistance loans. Further cuts will endanger the continuation of a supply of competent health care professionals, professionals necessary to meet America's health care needs.

In addition, totally eliminating the $20 million clinical training program, which provides critical support for academic teaching costs, will end all the projects funded in FY83 for mental health services education, research and demonstration and state manpower development in targeted areas. This program is the key to providing quality mental health services in this country, especially for underserved or unserved populations.

Block Grants

Funding health block grants at the level proposed by the President would actually result in a decrease for those already served by the ADMAHA block, the Maternal Child Health (MCH) block and the Primary Care grant because no provision would be made for the much-needed health funds Congress recently appropriated as part of the omnibus jobs package. We support the inclusion and continuation of these funds in the FY84 appropriation.

Without the additional monies states would be forced to continue policies under which 47 of them or 94 percent cut back on the MCH funding by reducing eligibility and/or health services. In addition, last year an estimated 725,000 people; 64 percent of whom are women of childbearing age, infants and children, lost services at the 239 community health centers whose funding was decreased. Other formerly catagorical programs such as lead-based paint poisoning, rodent control and drug abuse have experienced even more severe losses.

The President also asks that the family planning, migrant health and black lung clinics programs be folded in the Primary Care block grant. As it has twice in the past two years, . we ask Congress to reject this request.

Prevention

In recent years the federal government and the private sector have realized that one of the best ways to contain spiraling heath care costs, is to do whatever is necessary to keep people healthy in the first place. The federal goverment plays an essential role in health promotion and disease prevention.

No other body has the resources to conduct the necessary research and development; the immunization programs against measles, rubella, tetanus, polio and mumps; the education programs about drug and alcohol abuse and smoking as well as the positive programs about nutrition, physical fitness, and stress management. In addition, education about disease prevention, identification and control can do much to alleviate the steep rise in health care costs. Because prevention is cost-effective as well as being our best hope for controlling health care costs, we support adequate funding in the FY84 budget.

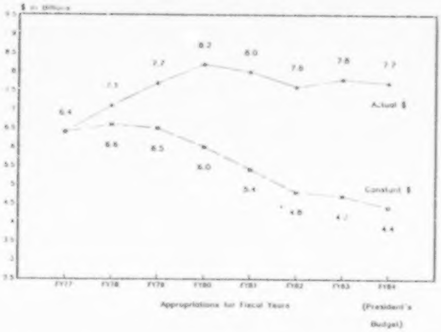
The funding chart included at the end of our statement outlines the Coalition for Health Funding recommendations for the Public Health Service. I wish to reiterate my thanks for the opportunity to speak before you today and would be happy to answer any questions.

COALITION FOR HEALTH FUNDING
Funding Recommendations

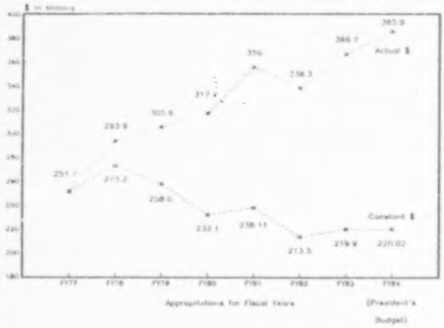
	FY83 Estimate	FY84 President's Request	FY84 CHF Recommendation
I. Food & Drug Administration	$361.7	$385.9	$400
II. Health Resources & Services Administration	637.4	445	595
III. Centers for Disease Control	243.4	269.1	310
IV. National Institutes of Health	4,002	4,077	4,489
V. Office of the Assistant Secretary of Health	95.3	123.2	123.2
VI. Block Grants			
Alcohol Drug Abuse and Mental Health Administration	469	439	532
Maternal Child Health	478	373	478
Preventive Health	86.3	86.3	98
Primary Care	360	295	327

COMPREHENSIVE FUNDING CHARTS

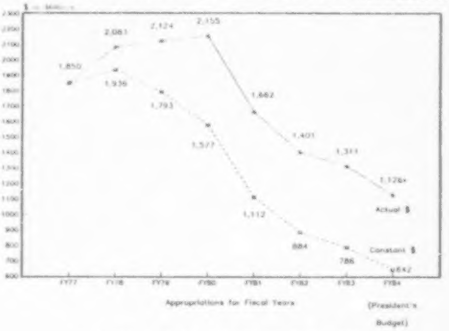
Public Health Service



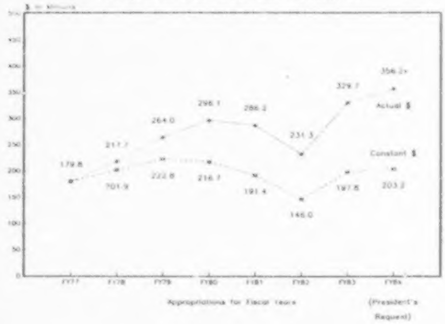
Food and Drug Administration



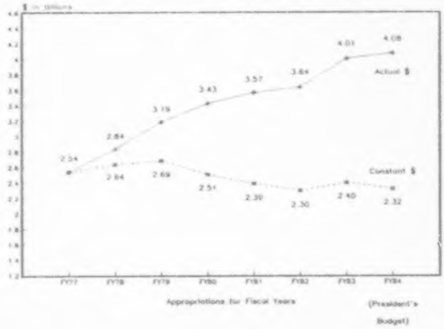
Health Resources and Services Administration



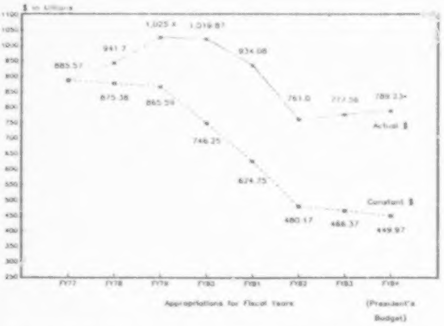
Centers For Disease Control



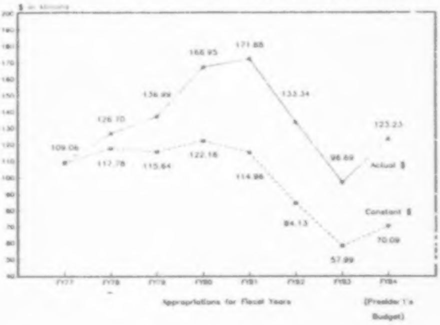
National Institutes of Health



Alcohol, Drug Abuse and Mental Health Administration



Office of the Assistant Secretary for Health



Prepared by the Coalition for Health Funding.

STATEMENT OF STUART SHAPIRO, M.D., MPH, COMMISSIONER OF HEALTH, CITY OF PHILADELPHIA; REPRESENTING THE AMERICAN PUBLIC HEALTH ASSOCIATION

Senator WEICKER. Dr. Stuart Shapiro, commissioner of health, Philadelphia; representing the American Public Health Association.

Dr. Shapiro, welcome and please proceed.

Dr. SHAPIRO. I'm Stuart Shapiro, health commissioner for the city of Philadelphia.

Mr. Chairman, in the hearing today and in other hearings of this subcommittee you're going to hear lots of statistics, lots of numbers, you're going to hear lots of pleas for more and more dollars, for this program or for that program.

My written testimony, I assure you, follows that pattern. However, in the few minutes I have today I'd like to move away from numbers and talk about the people.

I'd like to take you on to the streets of Philadelphia, a city that unfortunately is not atypical of many of our cities. The citizens of Philadelphia and the government of Philadelphia are feeling abandoned by the Federal budget. Human suffering has increased dramatically over the last 3 years, and the so-called safety net, which I know you personally fought to expand, has in fact turned out to be no safety net at all.

The budget policies enacted and proposed have turned out to be fiscally imprudent, economically inefficient, and morally wrong, at least as it reflects on my city.

Infant mortality—and I'll be specific—in Philadelphia has gone up. It hasn't gone down; it has now crept up. We had a downward trend. We were beginning to make a dent, as was happening in Washington and Detroit.

Data from the beginning of 1982 shows that trend reversing. Nonwhite infant mortality in Philadelphia is almost 26 per 1,000 births. The national average is 11.3. We in Philadelphia have lost probably 300 babies that if we had decent health programs appropriately funded, would not have died.

Let me continue on prenatal care for a second.

Senator WEICKER. A little ironic, isn't it, when you have a speculative policy such as the Baby Doe rule, and yet with conscious policy, you lose 300 babies in Philadelphia.

Dr. SHAPIRO. That's right. In Philadelphia the number of women appearing at hospitals with no prenatal care at all went up 91 percent in one hospital and 150 percent at another.

Hundreds of teenage girls are not getting adequate prenatal care because they don't have adequate resources. Previous Federal programs assured them of some of that prenatal care. Now hospitals are demarketing; we have two hospitals that, if you call up, are demanding hundreds of dollars before they'll let you through the turnstiles to get prenatal care.

You or I or our families might be able to negotiate a lower payment rate, but that 13-year-old or that 15-year-old girl is too scared: first of her pregnancy, often unplanned and unwanted; and second, of the billing clerks and the bureaucrats.

She doesn't know how to get through the system, so she gets no care. She appears at the hospital in the emergency room when her cervix starts to dilate, when she has cramps every 3 minutes. She has no medical records and she has no choices, and the results—and I think we have to talk about those results—are higher infant mortality, more mental retardation, more physical health problems, and ultimately, greater cost to society.

The Congress has recently seen evidence, and it's been published, of lead toxicity, and how you can treat it and how you can prevent it. We can't treat it adequately in Philadelphia; we can't detect it.

Consequently we have hundreds, maybe thousands of kids, 2 and 3 and 5 years old, wandering around Philadelphia streets in a stupor because of lead toxicity.

For drug and alcohol problems it's the same thing. Our medicare and medicaid budgets are forcing hospitals to turn people away and say to them, "The health of our institution is more important than the health of you as individuals."

You asked the representative of NACO earlier if the public and philanthropy and State government have picked up the budget cuts.

I can tell you in Philadelphia they have not. The Government Accounting Office can tell you; the Congressional Budget Office can tell you—they have not.

Obviously, the American Public Health Association, which I'm here representing, and the Conference of Mayors would like more money. But it goes beyond that. It really goes toward biting the bullet and realining and limiting some military inefficiency before we take any more money out of the poor.

One or two final comments. The block grant mechanisms have the potential to save money; in fact, they have eliminated some inefficiency. I've always been a personal strong advocate of categorical programs because they brought innovation.

Block grants, which we're living with today, do eliminate some inefficiency; however, there may be a mechanism to get more efficient health services, and that might be—and I think it would be a creative idea for this committee—to say, "Let's take three cities or five cities and write into the appropriations bill that they can receive a miniblock grant, taking the alcohol, the drug abuse, the mental health, the prevention, the maternal and child health. We're going to set up a demonstration program for three cities greater than 1 million population and eliminate the State level of bureaucracy, eliminate the fat at that level and say, rather than 50 block grants to the States, we'll now have 53. We'll take three cities and we'll collect some data and we'll see whether we can buy all the health programs and give some leverage to a health commissioner, or to a county commissioner, if it's a county, to begin to integrate services, because they're still fragmented because the State bureaucracy is doing the same thing that the old categorical programs do."

It would be totally in line with what the President wants to do, which is turn the money back to the State government.

Again, it's been a pleasure to be here. I hope that you and other members of this committee will respond and will begin to raise some of those dollars, but also look at more efficient ways to deliver services so we don't lose sight of those people who are in fact hungry, helpless, homeless, unhealthy, and often in despair because of the meat-cleaver approach that's been taken by the administration.

Thank you very much.

PREPARED STATEMENTS

Senator WEICKER. Dr. Shapiro, thank you very much. I'm sure you and I could talk for many hours on the subject. I very much appreciate your testimony.

Dr. SHAPIRO. Yes.

Senator WEICKER. Thank you very much. Your statement will be included in the record at this point, along with any other statements for the record on appropriations for the Department of Health and Human Services generally.

[The statements follow:]

STATEMENT OF STUART H. SHAPIRO

Mr. Chairman and distinguished members of the Subcommittee, I am Dr. Stuart Shapiro. I am the Health Commissioner of the City of Philadelphia and am here today representing the oldest and largest public health society in the world, the American Public Health Association. I am also authorized to speak on behalf of the U.S. Conference of City Health Officers.

Over the last two decades many federal programs have been developed to preserve the public's health and to meet special health needs. The general theory behind the development of these programs--from Maternal and Child Health, immunizations, and Neighborhood Health Centers, to Medicare and Medicaid--was that disease prevention and early treatment is appropriate, effective and relatively inexpensive in the long run. All studies have shown that the short term investment of health dollars reduces ultimate required expenditures.

It is therefore difficult to understand why these programs, which contribute to the public health in a cost-effective manner, have been singled out for negative attention (and sometimes elimination) by the current Administration. Tragically, the Administration's budget proposal for health and human services proposed earlier this year will undermine the health of our citizens and of our health care system. I too believe that we should balance the budget, but I am convinced that the direction taken by the Administration is wrong, and there are better ways to accomplish this laudable goal. Those involved in the administration and delivery of health and human services are troubled by the abandonment of important public health goals as a result of the cuts already enacted and now being proposed.

As Health Commissioner for the City of Philadelphia, I join with my colleagues here today to say loudly and clearly that the budgets being proposed and enacted are dangerous to the health of the citizens of this great Country. The suggested economies will be enormously costly in the long run. Human suffering will increase. The so-called "safety net" which is supposed to protect the truly needy from serious hardships is no safety net at all. Last year the "safety net" looked more like Swiss Cheese, with more holes than cheese; this year there is little cheese binding the holes together. In other words, the budget policies are fiscally imprudent, economically inefficient, and morally wrong.

The President's proposed budget will have a continuing negative effect on the health of Philadelphians. Funds have already been cut from many essential programs, and the Administration is proposing deeper cuts. Many areas in the already fragile and overburdened health care system are being strained beyond capacity, but, most of all, the budget is particularly lacking in funds to prevent disease and disability. Programs which assure care early in order to prevent more serious illness are being cut. Programs such as those providing care for pregnant women before they produce damaged babies; programs such as those providing services for young people before alcoholism and drug abuse are lifetime patterns; programs such as those providing early intervention for children whose emotional and mental development put them at risk for a lifetime of dependency; and many other programs providing preventive care have been hardest hit in the budget.

Today I will present an initial snapshot of what is happening in Philadelphia. It is incomplete. We are in the process of assembling all of the data. Surveys and questionnaires have been sent to over 1,000 service agencies, and the first returns are coming in. Daily we are seeing how bad things are, and how bad they are becoming. Let me give you some specific examples of the dangers of these false economies:

o Drug and Alcohol Treatment Program funds have been reduced in Philadelphia by 11% from 1981 to Fiscal Year 1983--not accounting for inflation. These cuts create a climate for violent crime. Two recent studies have shown that when heroin addicts join methadone programs, their rate of crime drops significantly as does their posession of handguns. Because there are no available treatment slot~~s,~~ addicts wanting and needing treatment are being told to steal to support an addiction. They will steal far more than this budget will save. An the health professionals at the National Institute of Drug Abuse knew this when the budget was prepared. Unfortunately, the 1984 Budget proposal proposes less real dollars for our citizens.

O Mental Health. The block grant for Mental Health Services has been reduced by this Administration by 20% not counting inflation over the last two years. If one factors in inflation the cut is more than 30% in real dollars. Next year it will be even more.

In Philadelphia, our data indicates that as unemployment has increased, there has been an increase in utilization of mental health services. Tragically, the City's capacity to deliver mental health services has diminished as the demand for services has increased. The stress of unemployment, and potential unemployment, results in the utilization of the most expensive treatment modalities thus further diminishing our already limited capacity to deliver services to all Philadelphians. The health professionals at the National Institutes of Mental Health knew this when the budget was prepared, and asked for adequate funds to provide services. But the budget proposal includes no additional mental health dollars.

o Maternal and Child Health Programs will have 20% less money available to give essential prenatal care to poor women. In terms of Maternal and Child Health Care, eliminating prenatal care is not cost-effective. The United States tragically ranks 14th world-wide in infant mortality. Infant mortality must go down. It will not with the program cuts being proposed by the Federal Government. These cuts are occurring in the face of scientific evidence that this care is effective in preventing birth defects, infant deaths and disabilities. High risk pregnancies, if we don't care for them, produce crippled, sickly babies who have no fair chance for normal productive life. This is not only inhumane, it is bad economics. It is far cheaper to offer prenatal care to a poor woman than it is to pay for a lifetime of special services and/or custodial care for a handicapped child. The health professionals at the Department of Health and Human Services know this. Yet their knowledge continues to be ignored.

A major reason that women in Philadelphia do not receive adequate prenatal care is that they lack financial resources. The State's Medicaid system is inadequate today, and if proposed legislation is enacted it will get worse. The funds under the MCH Block Grant are likewise inadequate. Many of the women who are unable to receive Medical Assistance early enough to pay for prenatal care are pregnant for the first time, and they are not now eligible for Aid to Families with Dependent Children. These women are often young teenagers who are most easily discouraged by a bureaucracy that is difficult to negotiate. The results of inadequate care are becoming obvious. After many years of a steady decline in the infant mortality rate both nationally and in Philadelphia, it has again begun to rise in this City. When the number of infant deaths in Philadelphia in 1981 and 1982 are compared, a disturbing picture emerges. Just when we were beginning to hold infant mortality down, the state and federal governments cut back programs, and the rate increased from 19.1 deaths to 21.2 deaths per 1,000 live births for all Philadelphians. However, among non-whites a population that is significantly poorer overall than whites, the rise is more dramatic. Between 1981 and 1982, the rate, based on preliminary data, rose from 22.4 to 25.6 deaths per 1,000 births. That is a 14.3% increase in just one year. That ratio is more than double the national average of 11.3%...and that is still too high!

- o The impact of these cuts will be compounded by the cuts in the Women, Infants and Children (WIC) Program that provides essential food supplements to hungry, malnourished pregnant women, mothers, and babies. In Philadelphia, there are at least 30,000 women, infants and children who are hungry. As a result of Federal cuts, this program will only serve 12,500 of our malnourished citizens... and the propcsed food stamp cuts will make the situation worse.

- o Immunization. While the proposed budget argues that we have been 95% successful in our immunization efforts, it would provide inadequate dollars to complete the job especially with the 40% rise in the cost of vaccine. If the Administration request for immunization funding is approved, fewer children will be immunized this year than were immunized last year.

- o Family Planning. At a time when the problems of teenage pregnancy for both mother and baby are being highlighted in the news media, the Administration is cutting back, rather than expanding, needed family planning services. Family Planning Programs have been an essential part of public health. We know that for every dollar spent on teenage family planning services $3 are saved in health and welfare costs. Indeed, it is estimated that teenage mothers are 40% more likely to give birth to babies premature and/or below normal weight. We cannot afford to give up those programs which encourage teenagers to use contraception, rather than produce babies for whom they are mentally, physically and financially unable to provide adequate care. Yet in Philadelphia between Fiscal Year 1981 and Fiscal Year 1983 we are losing 25% of our Federal Family Planning funds. Forgetting for a moment the effects of inflation, thousands of women may be denied family planning services as a result of these past cuts. The health professionals know this, and the health professionals know that the proposed inclusion of family planning on the larger block grant may further limit services.

- o The Lead-based Paint Program informs the public of the hazards of lead paint and provides for the inspection of dwellings as needed. Early detection of lead poisoning will save thousands of children from undergoing the pain of lead detoxification and millions of dollars in avoidable medical costs. Yet dollars for the lead paint program are being reduced. Over a two-year period, we will have lost 10% of the lead program. Next year it will be worse.

- o Venereal Disease and Tuberculosis Programs are being reduced. Partly because of the increasing refugee population, tuberculosis is on the rise. There is an epidemic of venereal disease in this country, with estimates that one in four American between the ages of 15 to 55 are affected. Over 1,000 babies will contract herpes infections at birth this year. Half of these will die, and half of the surviving babies will have serious birth defects. The incidence of congenital syphillis in babies has risen 60 per cent in three years. The incidence of venereal disease only goes down when it is prevented, detected, or treated. And the health professionals at the Centers for Disease Control know this. They know that the current proposals will not provide adequate funds to serve the thousands who need services. They know that the $5 million Tuberculosis grant programs to states should not have been eliminated, as the budget proposes.

- o In Philadelphia, almost 60% of inpatient hospital services are paid for by Medicare and Medicaid. The Federal budget proposals will cost our hospitals more than $50 million in unreimbursed care. Philadelphia hospitals are facing the unconsionable dilemma of either limiting care to the poor and the unemployed, or risking the end of all care by ending in bankruptcy. Many hospitals are now demarketing their services to poor patients.

In Pennsylvania the Medicaid Program reimbursement levels for doctors and hospital outpatient and emergency services have traditionally been among the lowest in the Country. Unfortunately, the current State budget maintains and the Federal budget proposal encourages that tradition of inadequate reimbursement...and further cuts are being contemplated.

o Flouridation. The Administration did not request any funding for fluoridation. Despite evidence that as much as $30 to $50 can be saved in dental care costs for $1.00 spent on fluoridation, less than half the population now receives this protection. In those communities where the water supply contains recommended levels of fluoridation, the incidence of dental carries has been cut in half.

While my examples are limited to only one city, Philadelphia, nationwide the numbers are far larger and the effects are more severe. We look to you to reverse the Administration's strategy. The fact is that money and lives will ultimately be saved if you adequately fund public health programs today.

The above are all cost-effective programs. Many have prevented the need for long-term hospital and custodial care. The theory is that these cuts can be absorbed by improved program administration and targeting carried on by the states and by the private and philanthropic community; unfortunately, the apolitical Government Accounting Office (GAO) and the non-partisan Congressional Budget Office (CBO) both say that is not the case.

When the Federal or State Government cuts a health department budget, the entire system of health care suffers. The fabric holding the health system together is very delicate. It is like a fine silk, not a sturdy cotton. If we destroy the fabric of the agencies providing care, or permanently weaken these agencies by forcing them to use endowments for routine operating expenses, reduce staff or cut eligibility, then even if by some miracle the program for economic recovery does work, we will have virtually no health system remaining.

The APHA supported the House passed budget, which we believe assures close to acceptable levels of funding for Function 550 programs, and strongly urges you to report an appropriations bill that provides public health dollars at or above the other body's recommendations. We endorse the funding levels for public health programs presented to you today by the Coalition for Health Funding.

In additon, APHA is committed to seeking passage and funding of child health legislation to improve preventive and primary care services under Medicaid, and to extend coverage to additional poor children and pregnant women. We are aware of child health proposals which are being discussed in the Senate and encourage this committee to take such new initiatives into account when you consider funding for Medicaid.

But the issues go far beyond those dollars. The issue is that our priorities must be realigned. I'm hopeful that this committee and this Congress will "bite the bullet" and take sufficient steps to examine and curb military inefficiency before hurting the poor any longer or increasing military spending any further.

Block grants do provide a mechanism that has the potential to assist local governments in the delivery of health services. I have a lways been a strong advocate of categorical health programs because they encourage innovation. Part of the cost of that innovation was some inefficiency. The block grants which we are living with today do eliminate some of that inefficiency.

I believe that I also have another mechanism to further assure that there are as few dollars used inefficiently as possible. One of the major reasons for structuring the block grants was to turn money back -- as a block -- to state and local governments. Unfortunately local governments today do not receive any money directly. There is still a layer of bureaucracy that, if eliminated, could increase the efficiency of our health care system. I would suggest that this committee add a provision to the appropriations bill that would allow the Department of Health and Human Services to make 3 - 5 experimental mini-block grants to local governments that serve over one million people. These experimental grants would thus increase the number of block grants (the number of states) to 53 or 55 but would allow some true experimentation in the coordination of services at the local level. For example, if the City of Philadelphia could negotiate with the Federal Government for a specific sum of money in Drug and Alcohol, Maternal and Child Health, Prevention, etc., we could truly integrate these services in a more cost-effective way. I don't believe this should be a wholesale new program of revenue sharing but rather a small experimental program. I would be pleased to discuss this with you and your staff at a subsequent meeting if there is any interest.

I am also hopeful that this Committee assures that adequate data is collected by the state and federal governments under the current block grant system and that we do not simply rely on anecdotal information when we come to evaluate the new federalism proposals of the last three years.

I hope my message is clear. I'm not opposed to living within a budget. There has been waste in the system. It has been eliminated. I'm not opposed to managing cost effective programs, but I am opposed to not facing human realities. Yes there are no doubt some welfare cheaters but we must not lose sight of real human realities -- that for that very rare person cashing in food stamps to buy whiskey there are many who are hungry, homeless, helpless, unhealthy and in despair. The President, the Director of Office of Management and Budget, and others who have been taking the meat cleaver to health programs must learn this. All they have to do is walk down the streets of Philadelphia.

In conclusion, let me once again emphasize the cost-effectiveness of the above-mentioned programs. Many have prevented the need for expensive long-term hospital and custodial care. It is pennywise and pound foolish to underfund expenditures for prevention and early treatment. The goal of a balanced budget and the federal government's responsibility to assure quality health care for all Americans are non inconsistent. To the contrary, both will be served only by adequate funding of public health programs. The programs are not current expenses; they are investments in the nation's future that pay handsome dividends over the long run, not only in terms of reduced expenditures for treatment but also in the strength and productivity of our greatest asset -- the American people.

Thank you. I would be pleased to answer any questions.

STATEMENT OF ROBERTA BALSTAD MILLER, PH. D., EXECUTIVE DIRECTOR, CONSORTIUM OF SOCIAL SCIENCE ASSOCIATIONS

The Consortium of Social Science Associations (COSSA), which represents more than 150,000 social and behavioral scientists across all the social science disciplines, welcomes the opportunity to present testimony on the FY 1984 budget of the Office of the Assistant Secretary for Planning and Evaluation (ASPE) in the Department of Health and Human Services (DHHS). This statement is directed toward two purposes. First, it discusses the FY 1984 budget request for ASPE in the context of the importance of the ASPE research program for DHHS. Second, and equally important, it takes strong issue with the recommendations of the President's Private Sector Survey on Cost Control (the Grace Commission Report), which calls for a transfer of the research functions of ASPE to one or more of the operating divisions within DHHS and the abolition of evaluation functions in ASPE.

We urge the Senate Appropriations Committee to support the Administration's budget request of $12.4 million for ASPE. Although this is down slightly from $14 million for this office last year, it is a reasonable, if minimal, allocation for the functions of that office. As part of the justification for the $12.4 million request for ASPE, as well as to help the Committee understand why ASPE should have an independent research budget, it is useful to describe the way in which research is currently organized within DHHS.

DHHS actually has five significant research functions, four of which are located in the operating components. The fifth is located in ASPE, which reports directly to the Secretary. The operating divisions with their own research budgets include the Social Security Administration (SSA), the Health Care Financing Administration (HCFA), the Public Health Service (PHS), and the Office of Human Development Services (OHDS). These operating divisions all have well-defined, although relatively narrow, program responsibilities -- SSA for income security programs related to the elderly, HCFA for a variety of health and health insurance programs, PHS for analyses of mental and physical health problems, and OHDS for research on the handicapped, on young people with special problems, on the aged, and others.

The concerns of each of these operating agencies are necessarily focused on the set of programs that fall under their area of responsibility. Typically, the research activities undertaken by the operating divisions are concerned with immediate policy issues that come to the attention of the division or the department as a whole. For example, SSA would appropriately worry about the consequences of extending the retirement age for the financing of the social security programs, or of changing the criteria for disability; HCFA would be concerned about the consequences of various insurance plans; PHS with the treatment of schizophrenia or of mental disorders resulting from stress; and OHDS with programs designed to place handicapped people into normal settings rather than specialized institutional settings; and so on.

The overall responsibilities of DHHS cover aspects of American life that are not obviously within the purview of any single one of these operating divisions. Moreover, DHHS has responsibility for three important kinds of research activities that clearly cannot be undertaken effectively by one or more of the operating divisions.

First, there are research issues that cut across the responsibilities of the various divisions. Such programs could be undertaken by some combination of the operating divisions, but it is risky to assume that cross-cutting problems will be handled by cooperative efforts. Often such problems are handled by no one.

Second, there are policy alternatives that need to be researched that are quite unlikely to be undertaken by any of the operating divisions with explicit program responsibility. For example, an alternative which involves elimination of a whole program or set of programs is unlikely to be seen as an appropriate research topic by the operating division that has that program responsibility.

In addition, DHHS currently administers a set of public programs required by a longstanding array of mandated public policies. The societal problems that these programs and policies were designed to ameliorate need to be continually monitored, old programs need to be assessed for their effectiveness, and potential new programs need to be evaluated.

DHHS thus has a major evaluation function, where the programs to be evaluated are those being conducted in the operating divisions. It goes without saying that evaluations should not be conducted exclusively by the organization or the individuals responsible for the program to be evaluated. At present, ASPE is supported to do part of the DHHS evaluation function through a funding set-aside (up to 25% of the resources earmarked for evaluation in the operating divisions). The rest of the evaluations are conducted by the operating divisions. In that way, the divisions most familiar with the program have a significant role in conducting the evaluation, but ASPE, with no direct responsibility for the program, plays a major role in the evaluation process.

ASPE's role is essential to the integrity of the evaluation process. For example, when there is suspicion that a particular program is poorly designed or inefficient, it is not wise to allow those with programmatic responsibility to evaluate the program. To have accurate evaluations in DHHS, there must be provision for independent evaluations.

An alternative, to discontinue DHHS evaluations in toto, is irresponsible in a time of fiscal stringency. Without maintaining a soundly based evaluation capability, an agency runs the risk of maintaining inefficient, ineffective, or needlessly expensive program.

The importance and usefulness of the ASPE research activities can best be understood by citing a few of the kinds of research projects that ASPE has supported.

Toward the latter part of the 1960s, there was considerable congressional and administration interest in the idea of an income security program that would take the form of a guaranteed family income with appropriate work incentives. The amount of the guarantee was to depend on family composition, and the guarantee level would be affected by the earning level of family members. This general idea was a response to the widespread dissatisfaction with the system of public welfare, which, while it provided income support, was widely thought to provide strong disincentives for those on public welfare to go into the labor market. The study was particularly important from a fiscal point of view because welfare costs the nation an estimated $10 billion per year.

The results of the study have had a major impact on thinking about welfare. Although the findings were basically negative, that is, aside from married white males, most other welfare recipients worked less if they had a guaranteed income, they prevented bad policies from being instituted. Equally important, they reoriented thinking about welfare reform.

About four years ago, ASPE initiated a series of retirement studies concerned with the long-term consequences for the U.S. economy and society of the changing age distribution of the U.S. population. These studies were designed to help DHHS understand the consequences of demographic changes on economic well-being, health status, the occupational distribution of employment, and investment, savings, and productivity growth. Because the retirement system currently absorbs approximately 5% of the gross national product (GNP), the effect of retirement and changes in the retired population cannot be ignored. We have already learned from these studies how to determine differences in the well-being of older people as compared to younger people. For example, we have learned that contrary to popular belief the elderly are generally well off as compared to the rest of the population.

This year ASPE is providing an important part of the support for what is clearly the most ambitious study of wealth undertaken in the U.S. since the early 1960s. ASPE's interest in the study, which is also being supported in part by the Federal Reserve Board as well as a number of other public agencies, is mainly in the assessment of wealth in the form of employer pension and social security rights. Hence the study will focus on wealth very broadly defined, including not only tangible assets like houses and durable goods and intangible assets like savings accounts, stock, etc., but also on wealth in the form of rights to private pensions earned through participation in the labor force.

ASPE's interest lies in the prospect that this study could shed some light on the crucially important policy issue of the determinants of personal saving behavior. If this study continues as now planned, it may eventually provide a fresh insight into one of the most vexing problems now facing U.S. policymakers -- the role of personal saving rates in the national economy and on the availability of capital.

These studies are illustrative of the menu of long-term problems and policy issues of overriding concern to DHHS. It is hard to believe that any of them would have been supported if all the research functions of DHHS were put into the operating divisions, as recommended by the Grace Commission.

We urge this Committee to provide full support for the ASPE budget recommended in the FY 1984 budget request. The Office of the Secretary in DHHS has massive responsibility for programs that affect all of American society. Without funds for putting in place long-term research activities designed to illuminate policy issues that cut across the different parts of DHHS, we will be less well able to cope with the challenging problems of the 1980s, the 1990s, and beyond. The budget request of $12.4 million is a minimum sum for the research functions that need to be continued to ASPE.

We also urge the Committee to support the maintenance of an independent evaluation function in ASPE. The need for continued policy and program evaluation in DHHS is indisputable. However, unless this evluation is done independently of program responsibilities, it will not be worth doing.

STATEMENT OF DON B. CHAFFIN, PH. D., PRESIDENT, ASSOCIATION O UNIVERSITY PROGRAMS IN OCCUPATIONAL HEALTH AND SAFETY, AND DIRECTOR, CENTER FOR OCCUPATIONAL HEALTH AND SAFETY ENGINEERING, THE UNIVERSITY OF MICHIGAN

ACCOMPANIED BY DR. CULVER

Senator WEICKER. The next witness is Dr. Don Chaffin, president, Association of University Programs in Occupational Health and Safety.

Dr. Chaffin, it's a pleasure to have you. Please proceed.

Dr. CHAFFIN. Thank you, Mr. Chairman. I'm joined at the table by Dr. Culver from California.

I greatly appreciate the opportunity to speak to this committee on behalf of academic programs in occupational health and safety.

Federal training funds, made available for such purposes through the National Institute of Occupational Safety and Health during the 1970's, provided the means to initiate academic programs in occupational health and safety training at various universities.

In recognition of the acute need of such program funding, Congress in 1976 authorized an expansion of the existing training programs to include the creation of 20 multidisciplinary educational resource centers, now referred to as ERC's.

During the subsequent 4 years from 1977 to 1980, the funding was expanded for this purpose from $2,900,000 to $12,900,000, and that allowed 12 of the intended 20 centers to be funded by 1980. This resulted in the existence of over 100 different degree academic programs by 1980, offering degrees related to occupational medicine, industrial hygiene, occupational health, nursing, and occupational safety.

I might add, the number of professionals graduating from these programs increased in proportion to the funding increase during that period, from 217 professional degrees in 1977 to over 750 in 1980. I plotted those in my formal testimony.

The development of the 12 educational resource centers in the late 1970's also provided a much larger continuing education program in occupational health and safety, and in 1977, in comparison, 1,600 professionals attended courses at the various universities, while by 1980 this was increased over 10,000.

Despite the success, though, of the academic programs to increase the number of well-trained professionals in the field. in the late 1970's the Federal funding was drastically reduced in subsequent years.

The reduced budget of today, $5,800,000 in NIOSH support for fiscal year 1983 has meant that only 60 academic degree programs are now functioning within the universities compared to 100 in 1980. The locations of those programs I've also shown on a map in my prepared testimony.

If no Federal funding is provided in 1984, as recommended in the administration's budget, the number of graduates completing their programs would drop to approximately 40 percent of the number graduating in 1981 and only about 25 graduate degree programs could be expected to remain viable in this country for years to come.

In retrospect, the decision by Congress in 1976 to expand the support of occupational health and safety training was wise, in our opinion. The universities responded rapidly to the challenge; they initiated a large number of new programs to meet the country's needs.

Those same needs exist today as in 1977. The number of new professionals needed in 1981—and that was the year when we graduated the largest number—was estimated by NIOSH to be seven times greater than the total output of the programs funded in 1981.

It should be clear from all of this, though, that the academic programs have not established a permanency. They did not have time, in that sense, to do that. The contracted economy also of the last couple of years has meant that the State agencies and private industry have not been able to increase support for such training over that provided in 1980.

Recall that the intent of the congressional appropriation for the ERC programs in 1976 was to have within 5 years 20 centers, each funded at approximately $1 million annually.

NIOSH's peer review process has established that 15 universities would qualify for such funding. If the originally intended funding of $1 million each for these 15 centers could be provided, the academic base needed to better meet our country's manpower needs and establish viable centers within each university in the future could have been achieved and will be achieved.

It must also be recognized that the single discipline training projects as well as these ERC's are vital.

In summary, we strongly urge you to consider restoring funding to a level of $16.5 million for the NIOSH training programs.

I might also add that we're concerned about the funding for the research grant programs. At present we're seeing only $6,500,000 in grant research money being allocated in the fiscal year 1984 budget, or being requested.

We would point out that this is only 13 percent of NIOSH's present research budget, and we would hope that you would increase that to allow the basic research necessary to understand the complex nature of occupational health and safety problems in the workplace.

Thank you.

PREPARED STATEMENT

Senator WEICKER. Thank you very much, Dr. Chaffin. I appreciate your testimony.

[The statement follows:]

STATEMENT OF DON B. CHAFFIN

Chairman Weicker:

I greatly appreciate the opportunity to speak to this committee on behalf of academic programs in occupational health and safety. Dr. Raymond Suskind and others met with this committee during the preceding two years for the same reason that I meet with you today. The past year's presentations demonstrated how federal training funds, made available for such purposes through the National Institute for Occupational Safety and Health during the 70's provided the means to initiate academic programs in occupational health and safety at various universities. In recognition of the acute need for such program funding, Congress in 1976 authorized an expansion of the existing training programs to include the creation of 20 multidisciplinary Educational Resource Centers (ERC's). During the subsequent four years (1977-80) funding was expanded for this purpose from $2.9 million to $12.9 million, which allowed 12 of the intended 20 Centers to be funded by 1980. During this period appropriate faculty were recruited, new curriculii which stressed the multidisciplinary nature of occupational safety and health were established, and a concerted effort to attract outstanding undergraduate science and health students to the field was initiated at the universities. This resulted in the existence of over 100 different academic degree programs by 1980, offering degrees related to occupational medicine, industrial hygiene, occupational health nursing, and occupational safety. These programs primarily resided in the 12 new Educational Resource Centers, with assistance of the single discipline training projects available in 29 other universities at the time.

The number of professionals graduating from these programs increased in approximate proportion to the funding increase, from 217 in 1977 to 747 in 1980. [These data are plotted in Exhibit 1, with the funding pattern shown at the bottom and the annual degrees granted at the top.]

The development of the 12 Educational Resource Centers in the late 70's also provided much larger continuing education opportunities for those already practicing in the field. In 1977 approximately 1,600 professionals attended courses at the various universities and within NIOSH. In 1980 this number increased to almost 10,000 attendees. [Exhibit 2 displays these trends in comparison with the federal funding.]

Despite the success of the academic programs to increase the number of well trained professionals in the field during the late 70's, the federal funding was drastically reduced in subsequent years, from a high of 12.9 million dollars in 1980 to the current 5.8 million dollars appropriated in the FY83 budget. Further examination of Exhibits 1 and 2 reveals the declining capacity to continue to provide the professionals needed in this field. The number of graduate degrees granted has already started to decline (despite programs using unspent funds sequestered from previous years to support students admitted to programs of two and three years duration). The drastically reduced budget of 5.8 million dollars in NIOSH support this year has meant that only about 60 academic degree programs are now supported within the various universities, compared to over 100 in 1980. The locations of these programs are indicated on the attached map.

If no federal funding is provided in 1984, the number of graduates completing their programs will drop to approximately 40% of the number graduated in 1981, and only about 25 graduate degree granting programs could be expected to remain viable in the Country for years to come. Further, the programs that would remain probably would revert to single discipline training utilizing faculty with existing but narrow expertise. These survivor programs would also have little capacity to meet the rapidly expanding demand for continuing education of professionals already in the field, with only one-third of the present courses expected to be available to such persons in 1984.

In retrospect, the decision by Congress in 1976 to expand the support of occupational health and safety training was wise. The universities responded rapidly to this challenge, and initiated a large number of new programs to meet the country's needs. Those same needs exist today as in 1977. The number of new professionals needed in 1981 was estimated by NIOSH to be seven times greater than the total output of the programs funded in 1981. Though the present manpower demand admittedly has weakened since 1981, the demand for well trained professionals still exceeds the supply, and with an upturn in our economy, the demand will increase further. Who will train these professionals with so many of the current programs failing due to the funding reductions? Furthermore, the federal cost of such education is low (approximately $7,000 for each degree graduate and $70 for each attendee in a continuing education course). Consider that the total cost of occupational injuries and illnesses is conservatively estimated by the National Safety Council at over 32 billion dollars a year as a result of over two million injuries and fatalities in the workplace. If a well-trained professional can prevent only a few injuries or illnesses he or she has easily paid for their education.

It should be clear from the preceeding that the new academic programs established in the late 1970's did not have time to achieve permanency in their home institutions. Many have already disappeared with faculty teaching in other more traditional fields, or going into private industry. The contracted economy of the last couple years has also meant that state agencies and private industry have not been able to increase support for such training over that provided in 1980.

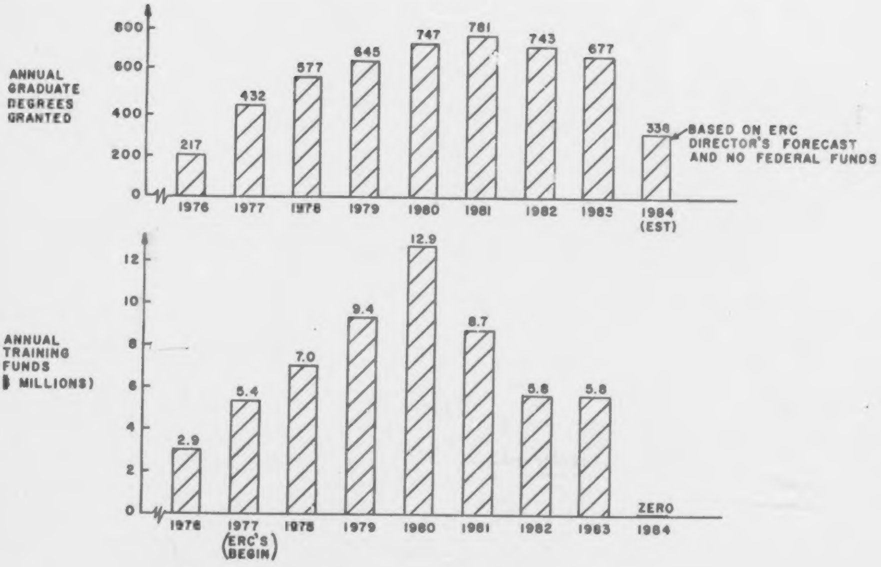
Recall that the intent of the Congressional Appropriation for the ERC programs in 1976 was to have within five years 20 Centers, each funded at approximately one million dollars annually. NIOSH's peer review process has established that 15 universities now meet minimum criteria to be Educational Resource Centers. If the originally intended funding of one-million dollars each for these 15 Centers could be provided, the academic base necessary to better meet our Country's manpower needs and establish viable Centers within each university in future years would be achieved. It must also be recognized that the single discipline training projects in other universities are vital, as they often produce special expertise needed in the field. These have been equally impacted by the training fund reductions over the last few years. These single discipline training project grants should be increased from the present $460,000 in FY83, to approximately 1.5 million dollars (i.e., proportional to the ERC increase). In summary, we strongly urge you to consider restoring funding at a level of 16.5 million dollars for the NIOSH training programs in the FY84 budget.

Lastly I would like to make a special appeal on behalf of the scientific community in occupational health and safety. Though the NIOSH research budget reductions have not been nearly as drastic as those in the training area, the FY84 Administration's Budget Request of about 52 million dollars is below that of 62 million dollars available in 1980 for research. Once again, conditions that created harm and death in the workplace then have not become simpler to understand. New chemicals, more complex manufacturing processes, and a workforce of older workers with more women in previously male dominated jobs have combined to create complex hazards and risks for workers. To understand how these conditions harm a person, and more importantly, how to effectively and economically prevent such harm will require a national research committment many times greater than reflected in the NIOSH Budget Request. There is a strong interest in the scientific community to support such an effort. Indeed, NIOSH currently is reviewing approximatley 350 research grant applications, the majority from young predoctoral, post doctoral and junior faculty. With their present research grant funding of approximately 4.7 million dollars perhaps 35 (10 percent) of these grant applications will be funded.

It is our understanding that the Administration has requested 6.5 million dollars of the total research budget for NIOSH to be available for research grants in FY84. This amount will provide the ability to fund many existing needs of the scientific community, but will not meet the needs for large scale research in occupationally related lung and cardiovascular disease, cancer, musculoskeletal disorders, neurobehavioral impairments, reproductive changes, dermatitis, and traumatic injuries. Because of the complex nature of these human problems in industry we believe research should be initiated by NIOSH. To do so will require the extramural research grant program to be increased from the requested 6.5 million dollars to 11 million dollars in the FY84 budget.

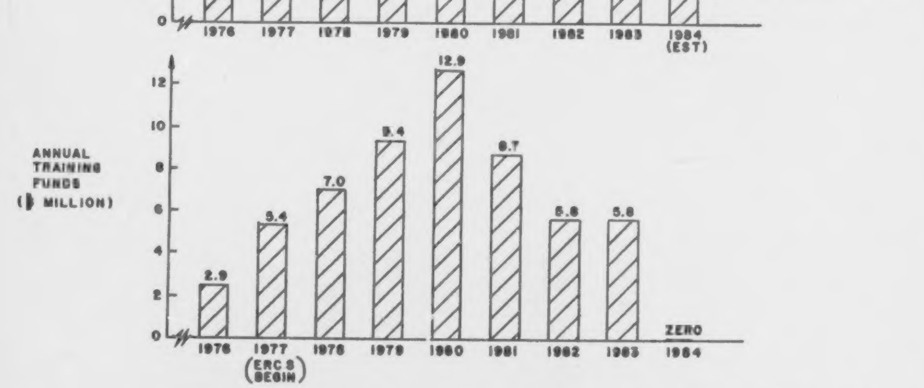
Thank you!

EXHIBIT 1

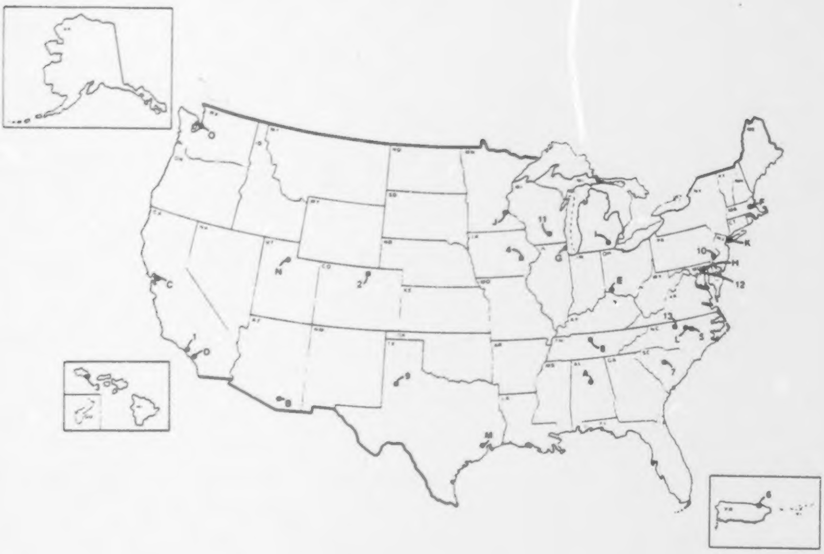


EFFECT OF FUNDING CHANGES ON NUMBER OF GRADUATES FROM BOTH ERC AND SINGLE DISCIPLINE PROJECT GRANTS

EXHIBIT 2



EFFECT OF FUNDING CHANGES ON NUMBERS OF ATTENDEES IN CONTINUING EDUCATION COURSES PROVIDED BY BOTH NIOSH AND GRANT SUPPORTED UNIVERSITIES



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Medical Center, University Station
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Vernon E. Rose, Dr., P.H., Director

B — **ARIZONA EDUCATIONAL RESOURCE CENTER**
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Department of Environmental Health SC-34
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PROJECT TRAINING GRANTS

	City		City
1. California State — Northridge	L.A.	7. Univ. of South Carolina	Columbia
2. Colorado State Univ.	Ft. Collins	8. McHarry Medical College	Nashville, Tenn.
3. Univ. of Hawaii	OAHU	9. Texas Tech. University	Lubbock, Texas
4. Univ. of Iowa	Iowa City	10. Temple University	Philadelphia
5. St. Augustine College	Raleigh, N.C.	11. University of Wisconsin	Madison
6. Univ. of Puerto Rico	San Juan	12. Catonsville Community College	Baltimore
		13. North Carolina A&T	Greensboro, N.C.

STATEMENT OF WILLIAM L. KEMPINERS, DIRECTOR, ILLINOIS DEPARTMENT OF PUBLIC HEALTH; REPRESENTING THE ASSOCIATION OF STATE AND TERRITORIAL HEALTH OFFICIALS

Senator WEICKER. Next we have Mr. William Kempiners, Illinois Department of Public Health, Association of State and Territorial Health Officials.

Welcome.

Mr. KEMPINERS. Thank you, Mr. Chairman. Before I start my testimony, Doug Delea, who's the president-elect of the association asked me to extend his personal regards to you.

Senator WEICKER. Good. He succeeds you here?

Mr. KEMPINERS. No; he's the president-elect. I'm chairman of the Federal Budget Committee.

Senator WEICKER. OK.

Mr. KEMPINERS. But seeing that he's from Connecticut, he asked me to say hello.

PREPARED STATEMENT

I do have a longer statement that I'd like to include.

Senator WEICKER. We'll put it in the record.

Mr. KEMPINERS. Thank you.

[The statement follows:]

STATEMENT OF WILLIAM L. KEMPINERS

Mr. Chairman, I am William L. Kempiners, Director of the Illinois Department of Public Health. I appear here on behalf of the membership of the Association as the Chairman of the Federal Budget Committee. Our Association represents the elected and appointed health officials of the 50 States and Territories of the United States. Directly affiliated with our organization are the Associations for Maternal and Child Health and Crippled Children's Programs, the Association of Health Facility Licensure and Certification Directors, State and Territorial Laboratory Directors and Epidemiologists, and State Nursing Directors. We appreciate this opportunity to present our views on the 1984 Federal Budget.

INTRODUCTION

The essence of my remarks today will deal with the discretionary area of the HHS budget. However, I would like to make some general comments. Our overall position on the Federal budget for 1984 is similar to the position adopted by the National Governors Association.

We are deeply concerned about the size and composition of the projected budget deficit for 1984 and subsequent years. Without an improved national economy, the States' revenues and fiscal conditions will continue to worsen. It is important to note that the States, unlike the federal government, can only provide services within their resource base. For 49 States the prohibition against deficit spending is a constitutional or legislative mandate. Therefore, the optimal solution to the current State dilemma is a national economy in recovery, based on real economic growth now and in the long term.

Ninety-six percent of HHS's budget ($276.3 B) is in entitlement programs and only 4% ($12.5 B) is in discretionary programs. In general, the 1984 HHS budget reflects emphasis on Medicare, health financing, cost containment and the Social Security changes projected for this year rather than on discretionary programs. For the majority of the discretionary programs the President's budget will result in another year of program operation without adjustment for inflation.

This last point is of vital importance to state and territorial public health programs. The major health expenditure indices, and especially the hospital cost index continues to rise at a 12 to 15% annual rate. Indeed, as HHS indicates in its January 31, 1983 press release:

- -- "In 1982 health care costs went up almost three times the national inflation rate;
- -- High health inflation is a long-term trend. Since 1965 consumer prices have risen two and a half times while hospital costs have shot up five and a half times;
- -- Over the last five years, Medicare costs have increased at an average annual rate of 19%.

Health care costs are climbing so fast that they may soon threaten the quality of care and access to care which Americans enjoy". This is the arena in which public health programs must operate. For example:

PROGRAM	1982	1983	1984	Change (84-83)
	(Budget Authority in Millions)			
Veneral Disease	43	48	49	1
Immunization	35	39	42	3
Block Grants	1330	1357	1357	--
Preventive	79	86	85	-1
Alcohol, Drug Abuse and Mental Health	428	439	439	--
Primary Care	449	460*	460	--
Maternal and Child Health	374	373*	373	--
State Certification (Medicaid)	20	41	35	(6)
State Certification (Medicare)	13	32	37	5
Social Services	2,400	2,450*	2,500	50
Community Services	336	342	--	(342)

While overall and for entitlement programs, the following situation exists:

HHS (in Billions)	246.6	273.5	285.2	11.7
Medicare	50,420	57,259	64,681	7,422
Medicaid	17,391	19,326	20,799	1,473

* The figures are from the Administration budget book and do not include the funding in the "Jobs Bill".

As can readily be seen, the HHS curative programs of the health care delivery system receive the lions share of the resources while the preventive programs receive a minuscule portion of the HHS resources.

Based on recent studies and logic, the biggest 'bang for the buck' is in preventive programs not in curative programs. Please do not misunderstand my meaning. There is a place for both approaches in the budget and preventive programs should never receive the lions share of funding. They are not as costly, but 4% is too low a figure.

The 1983 Supplemental Appropriations, the 'Jobs Bill', provides much needed relief for preventive public health programs. The additions of $105 million for MCH, $100 million for WIC, and $70 million for Community and Home Health Services will go a long way towards helping these programs recover the ground lost in the last three years due to inflation and level funding. However, long term health problems cannot be alleviated by a one time transfusion of money. Rather, long-term solutions require steady progress. Therefore, unless funding levels are maintained for these programs in 1984 and in future years, the situation can only deteriorate.

ASTHO POSITION ON THE 1984 HHS BUDGET

What are we suggesting for the 1984 HHS Budget? Basically, the Congress for 1984, and both the Congress and the Administration for the out years, need to implement a strategy to maintain these public health preventive programs given the high health care cost inflation. Hopefully, as the recovery continues and the recession diminishes funding for these programs can be increased.

Specifically, for the 1984 HHS Budget this would mean:

-- an increase in the Preventive Health Block Grant Budget Authority up to the Authorization level of $98.5 Million. This would represent an increase in program dollars in 1984 of 12.2 Million or 14% over 1983 appropriations.

-- an increase in the Maternal and Child Health Block Grant Authorization and Budget Authority up to $525 Million. The current base for 1983 is $478 million when the Supplemental Appropriations, the "Jobs Bill", is included. This increase would represent an increase in 1984 of $47 Million or 10% over total 1983 appropriations.

-- an increase in the Veneral Disease Program of $5 Million in addition to the proposed increase of $1 Million. This additional funding should be directed to the states to augment their capacity to handle the current epidemic problem of veneral diseases resistant to traditional treatment methods, especially Herpes surveillance and investigation. This would represent an increase in 1984 of $6 Million or 12.5% over 1983 appropriations.

-- an increase in the Immunization Program of $4 Million in addition to the proposed increase of $3 Million. The additional funding should be directed toward State immunization activities to enable them to remain at the record low of 1982 for vaccine-preventable childhood diseases. This would represent an increase in 1984 of $7 Million or 18% over 1983 appropriation level.

-- an increase of $53 Million in the Primary Care Programs, especially Community Health Centers and Family Planning. The current base for 1983 is $530 million, when the "Jobs Bill" Appropriations are included. The additional funding would allow for the expansion of low cost health care in currently underserved areas of the States and assist in providing greater statewide coverage for Family Planning activities especially those related to the poor, near-poor and teenage pregnancies. This increase would represent an increase in 1984 of $53 Million or 10% over total 1983 appropriation levels.

These are but some of the many examples which could be pulled from the public health discretionary portion of the HHS Budget. They have one thing in common. These programs are all affected by the same high health care cost inflation.

This leads to other important HHS discretionary programs which need budget adjustments in 1984. Specifically,

-- State certification for Medicaid facilities has been targeted for a $5 Million reduction in 1984 from the 1983 appropriation level. Due to the client population, (aged, mentally retarded, and poor) which receives care in the different hospital or 'nursing home' facilities and the need to protect them in terms of the quality and access to proper health care, we suggest an increase of $9 Million in 1984. This would represent an increase of $4 Million or 10% over 1983 appropriations to offset inflationary health related costs and the elimination of the proposed reduction in order to continue current enforcement of quality of care regulatory activities at the State level for these population groups.

-- State certification of Medicare facilities has been earmarked for an increase of $5 Million. We suggest that this increase of $5 Million or 14% in 1984 over the 1983 appropriations level is appropriate to offset 1983 inflationary health related costs. This is especially true as we look at the ever increasing numbers of aged in the nation, the anticipated expansion in the number of facilities, and/or lower cost modes of care needed to provide reasonable access and quality of care for these individuals.

CONCLUSION

If these recommendations are accepted, we feel that the maintenance and, hopefully, the expansion of cost effective preventive public health programs may help the States, local health care providers, and you to postpone, or avoid in the future such newspaper headlines as "$300 Billion Medicare crisis expected." (Chicago Tribune, April 14, 1983)

I would like to leave you with the documented cost effectiveness of preventive public health programs as provided in a 1978 study conducted in the State of Illinois.

--For every dollar spent on a measles vaccination, there is a benefit of $15.

--For every dollar spent on a hypertension program, there is a benefit of $150.

--For every 1 dollar spent on a rubella vaccination, there is a benefit of $151.

--For every dollar spent on a food service inspection, there is a benefit of $189.

Mr. Chairman, I thank you for the opportunity to present our views on the 1984 HHS Budget. I will be pleased to respond to any questions that you and other members of this Subcommittee may have.

Mr. KEMPINERS. I also might point out that I'm well aware of the task that you face today with the number of us coming and seeking more money, because before assuming the position of State health director, I was a member of the Illinois House of Representatives and served on the appropriations committee as minority spokesman in the human resources committee.

So I can appreciate what you're going through.

Without a healthy national economy the States' revenues and fiscal conditions will continue to worsen. It's important to note that the States, unlike the Federal Government, can only provide services within their resource base.

For 49 States the prohibition against deficit spending is a constitutional or legislative mandate. The optimal solution to the current State dilemma is a national economy and recovery, based on real economic growth now and in the long term.

The second point is of particular concern to State and territorial public health programs. For the majority of the discretionary programs, the administration's proposal will result in another year of program without adjustment for inflation.

The major health expenditure indices continue to rise at 12 to 15 percent annually. Health care costs are climbing so fast that they may soon threaten the quality of care and access to care which Americans currently enjoy.

Unfortunately, this is the arena in which public health programs too must operate. I'd like to point out that the jobs bill provided much relief in this area for preventive health programs.

However, long-term health problems cannot be alleviated by a one-time transfusion of money. Rather long-term solutions require steady progress.

Therefore, unless funding levels are maintained for these programs in 1984 and in future years, the situation can only deteriorate.

What are we suggesting for the 1984 HHS budget? I think Congress for 1984, and both the Congress and HHS for future years, need to implement a strategy to maintain these public health preventive programs at a consistent level, given the high cost of inflation.

Hopefully as the recovery continues, funding for these programs can be increased. Specifically, this would mean an increase in the preventive health block grant up to the authorization level of $98,500,000; an increase in the maternal and child health block grant to $525 million; an increase in the venereal disease program of $5 million, in addition to the proposed $1 million increase; an increase in the immunization program of $4 million, in addition to the proposed $3 million increase; an increase of $53 million in the primary care programs, especially for community health centers and family planning; an increase of $4 million for State certification for medicaid facilities and $5 million for State certification of medicare facilities.

The last point I'd like to make today, Mr. Chairman, is that 96 percent of HHS's budget is in entitlement programs, and only 4 percent is in discretionary programs.

This has been the case for a number of years with this agency. While the preventive programs receive a minuscule portion of the HHS resources, according to recent studies, the biggest bang for the buck is in preventive programs, not in curative programs.

Please do not misunderstand me, there's a place for both approaches in the budget, and preventive programs should never receive the lion's share of funding. But these are not costly programs, and I don't think 4 percent is realistic.

Finally, the expansion of cost-effective preventive public health programs may help the States, local health care providers and you avoid in the future such newspaper headlines as "$300 billion medicare crisis expected."

I know I would prefer to read "40 percent fewer lives lost to strokes in Cook County, primarily because of successful programs to control high blood pressure."

I might point out that strokes account for $1,200,000,000 a year in hospital costs alone, in addition to the cost of rehabilitation and disability.

Mr. Chairman, I thank you for this opportunity to be here with you today.

Senator WEICKER. Thank you very, very much. I appreciate your testimony and I assure you that we will give serious thought to all your requests.

STATEMENT OF WENDY WERTHEIMER, DIRECTOR OF PUBLIC AND GOVERNMENT AFFAIRS, AMERICAN SOCIAL HEALTH ASSOCIATION

Senator WEICKER. The next witness is Wendy Wertheimer, director of public and government affairs, American Social Health Association.

Ms. WERTHEIMER. Good morning, Mr. Chairman.

Senator WEICKER. Good morning.

Ms. WERTHEIMER. I'd like to first tell you something about our organization. We are the only national nonprofit group in the country working on venereal diseases. It has been in existence since 1912.

Our VD national hotline answers well over 150,000 phone calls a year with 80 percent of the people still getting busy signals. It gets more use than all national hotlines put together. There is obviously a great need for information.

We also have a program for people with herpes and we run a research program of our own.

VD is the most poorly served and poorly understood problem in this country. You've heard Dr. Shapiro talking about the great increase in infant mortality, but I think that what people don't understand is that a great part of this infant mortality is due to the problem of venereal diseases.

In fact, the real victims of VD are babies. This year congenital syphilis will be up 35 percent, and the fact that congenital syphilis exists in a civilized society is scandalous, as far as I'm concerned.

This year babies will die from herpes. Fifty percent of the babies who acquire herpes from their mothers will die, and most of the rest are severely brain-damaged.

This year there will be 52,000 ectopic pregnancies. That's greatly increased, even over the last 5 years. That's 52,000 babies who will die. At least half of those are directly attributable to venereal disease in the mother. That's roughly 26,000 babies who will die this year from VD.

That's a staggering feature when you think that AIDS is affecting 1,000 people—and we're very upset about AIDS and rightly so, and pouring money into the problem—but for years and years babies have been dying from VD, and this program has gone from $40 million for the grants to the States in 1981. It fell roughly $9 million during the year of 1982. We're back up now given the President's budget to where we were in 1981, but those 3 years have been devastating in terms of the effect that it has on disease.

When Federal dollars go up, disease goes down. And when Federal dollars go down, the disease goes up. And that has been true, syphilis is up 35 percent in the last year.

Gonorrhea that is resistant to penicillin, that is, it's really avoiding all control measures, has shown a sixfold increase.

As I said, more babies will die this year—die this year from VD than AIDS, toxic shock syndrome, and Legionnaire's disease put together.

In fact, more babies will be affected in 1 year by venereal disease than there were children affected by polio during the entire polio epidemic of the 1950's.

I think that it's a problem that we can no longer avoid and no longer keep saying, "Well, these are people who suffer the effects of their own actions." People who smoke suffer the consequences of their own actions and we spend $1 billion in cancer research and we're doing something—we're continuing to support the tobacco industry.

But these are people—people who have VD are all strata of this country, one out of every four Americans between the ages of 15 and 55 is affected by a venereal disease. One out of every seven teenagers has VD. The consequence of that is now an epidemic of sterility among teenage girls. One hundred and ten thousand women will be pathologically sterile this year from venereal diseases.

In fact, I read a statistic that of my age group of women born in the early 1950's, one out of every 28 of those women today cannot have children because of pelvic disease.

A $1 million increase to this program this year is totally inadequate, and I think that you have spoken often of compassion and I think it's the time to begin to have some compassion for this problem that is the only one that remains from the 1900's of communicable diseases that we are totally ignoring and that have gone beyond our grasp.

And I hope that finally, this year, something can be done to show some sense of support and caring for the needs of the people with this problem.

Thank you.

Senator WEICKER. What is the sum that we're talking about here? What was the 1983 appropriation?

Ms. WERTHEIMER. The 1983 appropiration was $40 million to States with about $8 million in operations funds.

Senator WEICKER. What was 1982?

Ms. WERTHEIMER. It was $31 million to States originally; with the $4 million supplemental, bringing the total to $35 million.

Senator WEICKER. Well, the statistics are awesome, aren't they?

Ms. WERTHEIMER. They are.

Senator WEICKER. Thank you very much.

Ms. WERTHEIMER. Thank you.

Senator WEICKER. Your statement will be included in the record at this point, as well as other statements submitted on the budget for the Centers for Disease Control.

[The statements follow:]

STATEMENT OF WENDY J. WERTHEIMER

Mr. Chairman, on behalf of the Board of Directors of the American Social Health Association, the only national non-profit organization directed solely on the problem of sexually transmitted diseases, I appreciate the opportunity to express our views on the FY 1984 Appropriations Bill.

If you check the hearing records for the past 5 years, you will find that, despite the magnitude and severity of the VD problem in this country, the only testimony on record regarding the programs for research and control of these diseases has been that of the American Social Health Association. Ours is the only voice in Washington to speak on behalf of those infected by the diseases, those at risk, their families, those working to prevent and control the diseases, and those looking for answers through biomedical research.

Our organization has been in operation since 1912, and with a current budget of only a million and a half dollars, we are struggling to fill the gap in services and information the government has left -- in keeping with the Administration's initiative for the private sector. Our VD National Hotline last year answered 140,000 callers in need of information and clinic referral. The phone lines are so jammed by callers in need that more than 80% of people who call get busy signals. Many of the callers are young people who have no where else to turn for help. Our Herpes Resource Center has responded to ~~more than 500,000~~ requests for information. These people were also in need of answers they could get no where else — not from their own doctors, and not from VD clinics. We have provided post-doctoral research training fellowships to 22 young investigators because the research training funds of the NIH have all but ended, and sexually transmitted diseases have never been a priority of NIH efforts.

The Venereal Disease Prevention and Control program of the Centers for Disease Control has been subjected to a roller-coaster of funding over the past three fiscal years. In fiscal year 1981, funding for the grants to states of the program was $40 million. In FY 1982 the funding was cut to $31 million for state grants. That level was increased by supplemental appropriation in September of that fiscal year to a level of $35 million. In FY 1983 the program was restored to its previous $40 million level. During this time the Direct Operations portion has remained relatively constant.

But as the funding has suffered cuts, and its professionals worried about their jobs, I would like you to know what has happened to the epidemic of diseases that program is mandated to control.

As you know from the testimony of the CDC, the VD control program is almost exclusively a program focused on syphilis and gonorrhea; and, in fact, given current budget constraints, the major emphasis of the program is gonorrhea. As a result of this emphasis and the need to make trade-offs in program priorities, syphilis is once again on the increase in this country. In FY 1982 there was an increase of 57.9% in syphilis cases over the cases reported in FY 1978, and an increase of 10% over the previous year (FY 1981). As a very sad consequence of that increase, there has also been an alarming rise in cases of congenital syphilis. Congenital syphilis cases reached an all-time low in FY 1979, and there has since been a steady increase - a 35% increase just between Fy 1981 and 1982. Mr. Chairman, there is no reason why in a civilized society we should still have infants suffering the devastation of congenital syphilis. In fact, it is telling that of all the communicable diseases that confronted society in the 19th century, the only ones to remain uncontrolled are sexually transmitted diseases.

Even as the program has invested its limited resources in gonorrhea control, new problems even within that disease program have prevented obstacles. Since 1979 there has been a six-fold increases in cases of gonorrhea resistant to penicillin, with a 64% increase in cases since 1981. Resistance to antibiotics makes control much more difficult and increases the risk of serious consequences.

Although the program has funds enough only to deal with syphilis and gonorrhea, other sexually transmitted diseases are raging in this country. Although more cases of gonorrhea are reported each year than all other reportable diseases added together, non-gonococcal urethritis is at least several times as prevalent as gonorrhea and has devastating medical consequences in men, women and in babies of infected mothers. A study published in 1982 found that stillbirth or neonatal death occurred ten times more often in women infected with chlamydia (the organism which causes most non-gonococcal urethritis). Yet the VD program does not have funds to adequately begin prevention and control of this disease.

The American Social Health Association has been trying to warn the governmentand the public about the epidemic of herpes since the 1970's. It was only in March of 1982 that the CDC finally announced that an epidemic of genital herpes has been occurring in the U.S. since 1966, with visits to medical practitioners increasing by more than 1,000 percent. It is estimated that as many as 20 million Americans (many estimate the number may be higher) suffer from herpes -- a painful and incurable sexually transmitted disease which can be particularly difficult for women, who may have a higher risk of developing cervical cancer and of possibly passing the disease on to their babies. Of babies who are infected with herpes, 50% will die, and half of the others will suffer permanent neurological damage.

I have heard it said, even in these hallowed halls, that there are no victims of venereal diseases, that people who get the diseases are suffering the consequences of their own actions. But, Mr. Chairman, that attitude is not only unfair but hypocritical. People who get lung cancer or heart diseases as a result of cigarette smoking -- the dangers of which are clear -- suffer the consequences of their actions. Yet we spend a billion dollars on cancer research and hundreds of millions on heart research, and the government continues to subsidize the tobacco industry. (The total budget for research on all sexually transmitted diseases totals $15 million).

But the fact is that there are victims of sexually transmitted diseases -- and a large number of them are babies. Probably the least understood aspect of the VD problem in this country is the impact of these diseases on infants. This year more babies will be affected by a sexually transmitted disease than children affected by polio during the entire polio epidemic.

There is, in fact, an epidemic of fetal death as a direct result of the diseases. The rate of ectopic pregnancy in this country has risen dramatically in the past decade, in direct relation to the rise in rates of venereal diseases, especially chlamydial infections. More than 52,000 ectopic pregnancies will occur this year (resulting in the death of the baby and serious risk for the mother). At least half of these ectopic pregnancies can be attributed to pelvic infections caused by one of these diseases.

This year babies will be killed or totally brain-damaged by herpes infection; babies will be killed by the ravages of syphilis; babies will be destroyed in the course of ectopic pregnancy caused by VD; and babies will die in the womb from maternal chlamydia infection. The number of babies who will die this year from venereal diseases is greater than the total number of deaths from Legionnaire's disease, toxic shock syndrome, and AIDS together. More than 26,000 infant deaths will be the result of ectopic pregnancy. The only way to control the epidemic in babies is to control the diseases in the general population.

Another sad result of these diseases is that there is now an alarming rate of infertility due to these infections. Not only are we now learning that some men can become sterile as a result of these diseases, we know that 110,000 women of child-bearing age this year will become pathologically sterile as a result of these diseases, 50,000 of them under the age of 25. In fact, it has been estimated that among my contemporaries, women born in the early 1950s, one out of every 28 of us will be unable to bear children because of pelvic inflammatory disease.

In short, the problem of sexually transmitted diseases is more than a national epidemic -- it is a national scandal. No epidemic in medical history has ever been of such scope or magnitude. One out of every 4 Americans between 15 and 55 years of age will be affected by a venereal disease. One out of every 7 teenagers today is infected by a venereal disease. The costs to society are tremendous, soaring to the billions of dollars. But how can you put a price on a baby who has died or to the emotional costs of a hysterectomy at age 20? The scandal is that so much of the disease is preventable.

Yet the VD Prevention and Control Program has never in its history had more than token support, and virtually no growth in the program in the past decade. The program has funds so out of balance with its needs that it has had to make difficult trade-offs resulting in the investment of almost all of its fund in one disease, gonorrhea. And there have been successes in that decision, as the gonorrhea disease rates have begun to come down for the first time in a decade. But in the meantime other devastating and dangerous diseases rage out of control.

Disease rates for communicable diseases can be shown to respond directly to funding. When federal dollars increase, disease rates drop, and vice versa.

I implore this Committee to finally show the concern this problem demands. The health of the young people of this nation depends on it. A society that can put men in space and develop an artificial heart cannot continue to tolerate congenital syphilis. Our record in controlling communicable diseases is clear -- tuberculosis, measles, polio, smallpox, rubella, whooping cough. The only diseases that remain are sexually transmitted diseases. The program to control these diseases has never had the support or the funding, or the chance, to successfully begin tackling venereal diseases and the consequences of VD. Each year we delay only makes the problem more monstrous. This year there will be 600,000 more cases of herpes, one million cases of pelvic inflammatory disease, 80,000 new cases of syphilis, more than 50,000 ectopic pregnancies, 110,000 women patholotically sterile, thousands of cases of penicillin resistant gonorrhea.

We are deeply concerned that despite the fact that authorizing legislation for the program provides that 5 percent of all funds appropriated for the program be allocated for projects of information, education, research and demonstration, only two grants for such programs are currently being funded. Budget constraints have prevented such grants, but education and public information are the first line of prevention, and for a disease like herpes, is the only prevention we have.

The projects of the VD program are critically important. A recent study showed that medical students today receive only an average of 6 hours of training regarding venereal diseases. The Training Centers of the VD Control program serve an important function in providing much needed training programs for clinicians.

The venereal disease epidemic has raged for years, fueled by complacency, fear, shame, silence, ignorance and inattention. It is within the power of this Committee to begin to change fifty years of institutionalized neglect. I urge you to show the leadership and compassion to bring about this change and provide full funding for the venereal disease prevention and control program, $50 million for grants to states and $15 million in direct operations.

I thank you for the opportunity to express our views.

STATEMENT OF THE GAY RIGHTS NATIONAL LOBBY

What appeared to be several isolated cases of rare and unusual diseases in early 1981 has now spread--uncontrollably--becoming a major public health epidemic, hitting over 1300 people in thirty five states and resulting so far in over 500 deaths. AIDS--Acquired Immune Deficiency Syndrome--is a breakdown of the body's immune system, leaving the victim highly susceptible to Kaposi's Sarcoma (a rare skin cancer), Pneumocystis Carinii Pneumonia (a usually fatal lung disease), and many other opportunistic infections. Fewer than fourteen percent of AIDS victims diagnosed three years ago are alive today. What is equally horrifying is that we still do not know the cause of the syndrome and, therefore, still have no knowledge about prevention, still have no knowledge about transmission, still have no knowledge about treatment, and still have no knowledge about cure.

Alarmed by the growing epidemic, the United States Conference of Mayors has established an AIDS Task Force to appeal for federal help. The Mayors, calling for federal attention to the frightening public health problem are asking for information, training, and technical assistance to cope with the growing burden on the cities' public health facilities. The Mayors' AIDS Task Force realizes that research into the origins of the disease remains beyond the capacity of any one city. In this era of limited local resources, the CDC and the NIH must develop an appropriate and adequate national response. They need adequate funding to do so.

AIDS has already taken twice as many lives as Legionnaires' Disease and Toxic Shock Syndrome combined. AIDS is not isolated to specific geographic communities, nor to specific groups of people. This epidemic warrants a major, federally coordinated and federally funded biomedical research effort combined with a coordinated campaign to educate the public and health care providers.

At a special order focusing on AIDS in the House of Representatives on May 3, 1983, sponsored by Representative Ted Weiss of New York, Representative Joseph Addabbo of New York said:

> I feel great sadness that our Congress has not reacted more quickly and effectively in addressing the AIDS epidemic....Without some type of immediate action on our part, this disease will reach even more diverse areas throughout the United States.... At least, we, as Members of Congress have the power to provide that available means and money which will enable the experts to find a cure for AIDS before it is too late.

There has been some response. Congress provided a supplemental $2 million to CDC's FY83 appropriation for AIDS-related research. This additional funding did help, but the CDC and the NIH had already been severley crippled in their ability to maintain their already existing activities by the Administration's budget cuts.

Many Members of Congress have responded to the call for increased funding for CDC and NIH by supporting FY83 supplemental appropriations to these agencies for increased AIDS activities. This epidemic requires continuing attention.

We ask that the Committee appropriate an additional $10 million to CDC and an additional $20 million to NIH for FY84 for the specific purpose of allowing these agencies to continue and to expand their AIDS-related activities.

The CDC needs additional, targeted funds to:

- extend field surveillence work;
- increase laboratory investigation;
- provide training and education to health care providers;
- establish and enlarge networks to disseminate information.

Field Surveillance: CDC needs to conduct extensive epidemiological investigations and to begin long-term followup studies not only of AIDS patients but also of emerging risk groups. This type of information is crucial to finding a cause and a cure for this disease.

Laboratory Investigations: CDC needs to expand laboratory work to isolate the cause of AIDS.

Provide Training and Education: Many health care providers, because of their ignorance of the disease and of their patients' backgrounds, are not adequately prepared to provide the quality medical care which is expected of them. The CDC in cooperation with public health departments, professional health associations, and community organizations, needs to educate both the public and health care providers about AIDS and its treatment.

Dissemination of Information: The mysterious nature of AIDS contributes greatly to the anxiety felt by both the patients and the public at large. The CDC needs to remove as much of the mystery as possible by keeping the public and the medical community informed about the disease. Networks for dissemination of information must be expanded and promoted.

The NIH needs additional funding to grant additional research activities. Additionally, NIH should be urged to expidite all research projects on AIDS. AIDS is a top priority at NIH, but funds must be made available to enable the Institutes to conduct the required research.

We urge that the Senate assume the leadership role this public health emergency demands. So little is known about this disease. The scope of this syndrome, already broad, might escalate to even greater levels. By appropriating targeted, additional funds to CDC and NIH for expanded AIDS related activities, the Senate will be fulfilling its responsibility to the American people to fight this new and frightening epidemic.

STATEMENT OF GERTRUDE ENGEL, AMERICAN HEALTH EDUCATION FOUNDATION

Mr. Chairman and the illustrious members of the Appropriations Committee, I am Gertrude Engel.

I represent the American Health Education Foundation and our more than 600,000 readers. Also, Mr. Victor Earl Irons, our 88-year-old Mr. America for Health from Cottonwood, California. My previous commentaries were accepted and published (1980-1981-1982) volumes as part of my research dedicated to health practices.

We fervently pray for the Federal government to assume a full scale ban of fluoride from drinking water. Water is the universal drink and cancer is the universal disease.

However, it is now under a Health and Human Services status functioning under a block grant program, giving states and local communities freedom of expression to accept or reject fluoridation.

The function of a public water supply is to provide safe drinking water and not to serve as a vehicle for dispensing drugs to treat people. Fluoride is one of the daily pollutants in our air and water which is increasing the incidence of cancer, heart and genetic diseases. We present our latest concepts and ask, please, that they be included in the record.

Excerpts follow:

Dr. Hans Nieper, world renowned cancer specialist from Germany, visited Washington, D. C., May 5, 1983. My interview was most informative. We learned that fluoride is carcinogenic and causes brain damage in children.

Casimer R. Sheft, D.D.S. reports, "Fluoride in drinking water contaminates all foods and drinks bottled or canned with polluted water and adds to our total daily intake of fluoride by as much as five times. I am still attempting to get the truth to the people so that a ground swell of public outrage would rise up and stop this health disaster before too much more more harm is done to the innocent victims of this disastrous scheme. Fluoride does not cause a reduction in tooth decay. That is a fallacy. There is not a single shred of scientific evidence that fluoride reduces tooth decay. In fact a $100,000 reward offer (in effect for over 20 years) will be given to anyone who can produce the one double-blind laboratory study which shows that fluoride reduces tooth decay and is safe to consume."

Dr. Dean Burk (U. S. National Cancer Institute-1939-1974 Retired)

"Fluoridation and artificial fluoridation have been reported to induce more documented human cancer deaths in the United States (currently at the rate of some 50,000 per year) and to do so with a shorter latent period (only 2 - 4 years, instead of commonly 10 - 30 years), than any other known chemical involved in the field of public health hazard. Evidence supporting these two summary statements has been published many times, and has been confirmed, unrefuted (even though disputed), in the four prominent American and British courts of law where these matters have been brought to issue, with all the evidence having been taken under oath and with extensive cross-examination by and of leading world disputants and counsel, all yielding a total of some 30,000 pages of recorded testimony. This testimony included extensive referencing and reporting of thousands of articles and books describing many other medical harms, lethal and otherwise, to human health caused by fluoride and artificial fluoridation that obviously cannot be recapitulated in any detail here but demonstrably well-known to EPA officials over the past decade."

The delegates of the New York State PTA convention recently voted overwhelmingly to urge all PTA units to discourage the establishment of, and eliminate the existing flouride school mouth rinse programs.

Levittown, Long Island. This community of 50,000 people has stopped a a 29-year practice of adding fluoride to the water supply to help fight tooth decay. "It is a potential enzyme inhibitor that can cause a headache in some and cancer in others." It was a clear preference of the residents who responded not to continue fluoridation.

Forty-one communities held fluoridation referendums in 1981. Of these, 33 said no fluoridation and 8 said yes.

American Chemical Society admits fluoride is not as they claimed to have thought, a harmless "inert" chemical but a cumulative poison which is interfering with our enzyme and DNA systems-can cause cancer, birth defects, genetic damage, allergy response.

Alton, Illinois - Fluoridation ruled illegal.

Circuit Judge Ronald Niemann announced that he had declared unconstitutional the Illinois law requiring fluoridation of municipal drinking water. He ordered that the Illinois Public Health Department and the State Environmental Protection Agency stop enforcing the law.

I personally spoke with Judge Niemann and respect his wisdom whereby he declared that a"risk exists of serious health hazards" caused by fluoridation.

His ruling covers the entire state.

Forced fluoridation, Niemann wrote, violates the process guarantees of the state constitution and amounts to "an unreasonable exercise of police power."

We anxiously await the decision of the Illinois Supreme Court pending the appeal as to what effect the ruling would have statewide.

We humbly request, please, that the Virginia State Legislature will reconsider the fluoridation issue.

Please take the advice of the late Dr. Philip Zanfagna, who explained, "There is no safety factor in fluoridation." The well-known physician pronounced his strong opposition to the use of fluoride in public water systems. He spoke of the compulsory fluoridation law as denying dialysate patients a chance for survival. He spoke of fluoridation as "Legalized Malpractice" with no proper safeguards, and that an unbiased legislative committee is needed.

STATEMENT OF CHARLES LIEBOW, D.M.D, Ph. D, ASSOCIATE SCIENTIFIC DIRECTOR, NATIONAL PANCREATIC CANCER PROJECT; ASSOCIATE PROFESSOR OF SURGERY AND PHYSIOLOGY, LOUISIANA STATE UNIVERSITY; REPRESENTING THE CANCER GROUP

Senator WEICKER. All right, next we have Dr. Charles Liebow, associate professor of surgery and physiology, Louisiana State University; representing the Cancer Group. Is that correct?

Dr. LIEBOW. That's correct.

Senator WEICKER. Dr. Liebow, nice to have you before the committee.

Dr. LIEBOW. Thank you. The cancer group is a group of lay professional people concerned with the war on cancer. I'm also representing the organ site program group.

I'm here to ask for two things, namely, support of the American Cancer Society budget request, that they're going to present to you, because this is a reasonable, usable, and performable budget.

Second, I wish specifically to ask for an allocation of $27 million for the organ site program, the same allocation that was given last year.

Why am I here? The organ site program represents the prime example of targeted research aimed at dealing with the devastating series of cancers which have been receiving inadequate attention.

These are cancers of the prostate, pancreas, bladder, and breast. These cancers are killing over 100,000 American citizens every year.

This program is designed and targeted to aid these victims and to use research in aiding these people.

The R–01 program, the basic research program, works effectively by a trickle-down philosophy. They feel that science that's good will eventually produce benefits that are good for society.

The R–26 program agrees with this, but they go farther and say "that certain areas need strengthening, certain areas need targeting, and certain areas need help. And these areas should be helped by a targeted program."

The people who have cancer—over 100,000 victims we're talking about each year—need this help now. They can't wait till an overall cure is found for all cancers; they're dying now.

The R–01 and R–26 programs can be compared to serendipity versus design. An analogy can be given that the R–01 supporters say that Fleming's discovery of penicillin could not have been planned.

The R–26 supporters agree with this, but it took 14 years, it took a world war, and it took some very fortunate turn of events to finally bring the discoveries of Fleming to the benefits of mankind.

The American society can't afford this haphazard way of filtering down this research: they need some specific targeting and they need efficiency, and the R–26 program provides this efficiency.

The R–01 and R–26 programs are not competitive; they're complementary. The R–26 program utilizes discoveries of the R–01 program to benefit the patients and fight the diseases that we're talking about.

The R-26 program only amounts to approximately 3 percent of the NCI budget. It's, therefore, not in the realm of competing with the R-01 program.

The National Cancer Institute has slated the organ site program for diminution to extinction. The National Cancer Advisory Board has opposed this. The chairman of the National Cancer Advisory Board and the chairman of the Organ Site Program Subcommittee of the National Cancer Advisory Board concur that if we don't have strong definitive legislation to keep this program alive, this program is going to be done away with.

We need strong, definitive legislation because last year in this committee when you passed report language asking for this program to be kept alive, this was ignored and this program is being killed.

The other groups have been told that if the organ site program gets its budget, this money will have to be taken away from them. This produces an internecine war among scientists.

Scientists can't squabble over the money. It's the responsibility of Congress to decide where this money should be allocated and to prevent this kind of war. It's also the responsibility of Congress to provide enough money so this kind of internal squabbling is not killing the program.

We need legislation to prevent this. We need sufficient support and the American Cancer Society budget provides this.

Congress can cure the war on cancer. We ask for your help.

Thank you.

PREPARED STATEMENT

Senator WEICKER. Dr. Liebow, thank you very much, and I certainly concur with your remarks that for Congress or the executive branch to take such actions and have the various scientific groups fighting among themselves is just as despicable in my opinion as having the various disabled elements of our society fighting among themselves, which is also the case.

I thank you very much for your testimony.

[The statement follows:]

Statement of Charles Liebow

I. BACKGROUND

A. CONCEPT OF TARGETED RESEARCH AND THE ORGAN SITE PROGRAM

In 1971 the National Cancer Act was passed by Congress to provide special emphasis toward combating cancer, a number one health problem in the nation. This act was designed to aim the vast American biomedical research community at dealing with the terrible public problem of cancer. Consistent with this goal, and because of the passage of the National Cancer Act, the Organ Site Program (OSP) was developed. The OSP was initiated because certain cancers with a terribly high impact on society were undergoing inadequate investigation.

Four diseases were targeted for this special effort. These included cancers of the large bowel and rectum prostate, urinary bladder and pancreas. Cancer of the large bowel and rectum represent the second largest cancer killer; accounting for 55,000 deaths per year (as of 1981) in the United States. Cancer of the pancreas is the fourth most deadly cancer killer in the U.S.; accounting for 22,000 deaths per year. Prostate and bladder cancers present major health hazards because of their high incidence. The need for recruitment of basic scientists, as well as clinicians, in these areas can be seen in the following example: Pancreatic physiologists represent only about one half of one percent of all physiologists in this country. This means that there is only a very small nucleus of scientists with the expertise to lay the ground-work for this major health problem.

B. DEVELOPMENT OF THE ORGAN SITE PROGRAM

To remedy this lack of attention, committees of nationally renowned scientists were convened to target research efforts toward dealing with these diseases. These committees were charged with: (1) developing a broad research plan to combat these diseases; (2) attracting researchers into these understaffed areas; (3) improving communications amongst the various disciplines impinging on these diseases; and (4) transferring the technological advances in these fields to direct benefit for the population. To implement the first two charges, a new granting program, the R26 program, was developed.

C. ROLE OF THE R26 PROGRAM

The R26 program is a granting program for investigator-initiated research. It is run similarly to the R01 program. Both programs have committees of expert scientists, selected by NCI and NIH, which review grants, both have NCI staff supervision and both exclude review of grants submitted by members of their own committees. Some critical differences, however, do exist between the R26 and R01 programs. R26 review includes: (1) review for program relevance as well as scientific merit; (2) review by a multidisciplinary group organized around a specific disease rather than around a single discipline; (3) review of only 20-30 grants per session rather than approximately 150; and (4) funding through a special budget designed to stimulate these understaffed areas. On the other hand, R01 Study Sections are instructed to review grants for their intrinsic scientific merit alone without regard for the country's need for any individual program. R26 groups review the status of the particular disease they are responsible for, develop a plan to fill missing gaps in knowledge, communicate these needs to the scientific community and implement the plan by prioritizing the research they review. For example: Suppose an R01 program reviews five, grants for bladder cancer having acceptable scientific merit; three testing the effectiveness of a specific anti-tumor drug, one for radiation therapy and one examining a new epidemiology theory. If the three similar drug studies are reviewed as having the best scientific quality, and money exists to fund only three studies, the R01 program will fund these drug studies and leave the other two unfunded. The R26 program, however, will say that the drug study is necessary, but only the best of the three would be funded in order to fund the two other scientifically meritorious studies. This will help to fill gaps in knowledge concerning these areas and help to balance scientific efforts amongst all needed disciplines. Another example of R01-R26 differences involves the distinction between new theories and the application of these theories to a disease entity. A recent R01 review of a grant referred by the OSP minimized the importance of the relationship between pancreatic cancer and hepatitis B virus. The R01 Study section stated that this relationship was already proven for liver cancer and recommended that the grant not be funded because it did not represent novel science. Establishment of such a relationship might yield an approach toward prevention of pancreatic cancer, and would therefore be considered of vital importance by an R26 review group. This weighing of program relevance and the needs of a particular field are vital elements in the R26 program.

The R26 review is multidisciplinary. R26 review groups have surgeons, internists, radiologists, carcinogenisists, epidemiologists, pathologists, biochemists, cell biologists, etc., all working on a specific cancer site. R01 groups are single discipline. A whole review group may be composed of only molecular biologists and each member may have a different organ site specialty. The perspective of the multidisciplinary review allows for the evaluation of a project in terms of its impact on a specific disease process. It also prevents inappropriate placement of a grant application in a committee not constituted to evaluate a particular scope of research.

Fewer grants are reviewed at a session. Though R26 review costs slightly more because of time spent on each grant, the quality of review is better. Instead of one, or at most two, primary review(s), as in the R01 system, the R26 program utilizes five or more. Furthermore, the primary reviews are from both committee members and non-committee experts. This allows for a broad, balanced, specialized review frequently unavailable in the R01 program.

The same committee that develops the program plan implements it and reviews the related applications. This prevents loss of direction. Decisions of funding allocations are made by the committee of experts most familiar with the work and the field.

The R26 program was developed to stimulate specific areas. Growth in R01 programs is serendipitous. Hopefully, areas needing study will eventually attract the right researchers. Growth, however, is usually unbalanced. Areas with the most researchers produce the greatest number of results and the greatest number of students. Since most researchers are in these fields, R01 review committees are filled with scientists from these areas. Accordingly, the scientists are sensitized to these areas and review of applications in the area of their expertise is more favorable. This attracts more investigators into the popular areas and compounds the imbalance and maldistribution of researchers. The R26 program culls its reviewers from the underdeveloped areas, and with the money specifically allocated to these areas, this partially redresses the investigator imbalance.

The R26 program is not intended to replace the R01 program. Development of the best scientific leads independent of a targeted area still holds the best hope for long-term progress in science. The R26 program is a complimentary program which provides the most rapid utilization of scientific discoveries for the benefit of the population. It has represented only a small adjunct to the R01 program, representing 1-3% of the total NCI budget. The R01 program existed before the R26 program and has existed in parallel.

D. ACCOMPLISHMENTS OF THE ORGAN SITE R26 PROGRAM

The accomplishments of the OSP-R26 program are great and undisputed. This program has attracted many researchers and has stimulated important work in targeted areas. It has promoted exchange, interchange and collaboration amongst scientists and clinicians. Models for specific cancers have been developed, characterized and disseminated to other researchers. This has opened up areas to a whole spectrum of new investigators. New theories concerning etiology, control, classification, diagnosis and treatment have been developed. Workers in the field recognize the importance these programs have had on the scientific momentum against these diseases.

II. CRISIS

A. NCI ADMINISTRATIVE PLANS

Since 1980, the NCI Administration has systematically reduced the budget of the OSP-R26 program. The R26 program funded $4,295,190 in new and competing renewal grants in 1979. Support dropped to $3,668,101 in 1980 and finally to less than $2,000,000 in 1981. The level in 1982 was only slightly above that in 1981 and it is projected that funding in 1983 will be similar. The OSP has been subjected to seven reviews in its eleven year existence. Though these reviews were mostly favorable, the last review was interpreted by NCI staff as calling for major revisions. The NCI Director, at the November meeting of the National Cancer Advisory Board - Organ Site Subcommittee, explained the rational for eliminating the R26 program. He said that although the OSP was successful, fiscal restrictions and a Congressional mandate for funding 5000 new investigator-initiated grants dictate that changes must be made. The mandate, he said, could be met by either: (1) funding more R01 grants instead of P01 (Program Projects) grants because R01 grants cost less; (2) counting each proiect in a P01 as a separate grant; (3) taking money away from other programs, like the centers program, to provide additinal funding for R01 grants; or (4) eleminating the R26 program, whose grants are investigator-initiated but do not count toward the 5000 goal. All but one of these strategies (3) provide no additional research effort, but merely provide the accounting appearance of sustained effort. As explained in the previous sections, R01 procedures cannot replace the R26 system. Eleminating a successful and productive program in order to provide accounting legitimacy seems terribly wrong.

B. NATIONAL CANCER ADVISORY BOARD ACTIONS

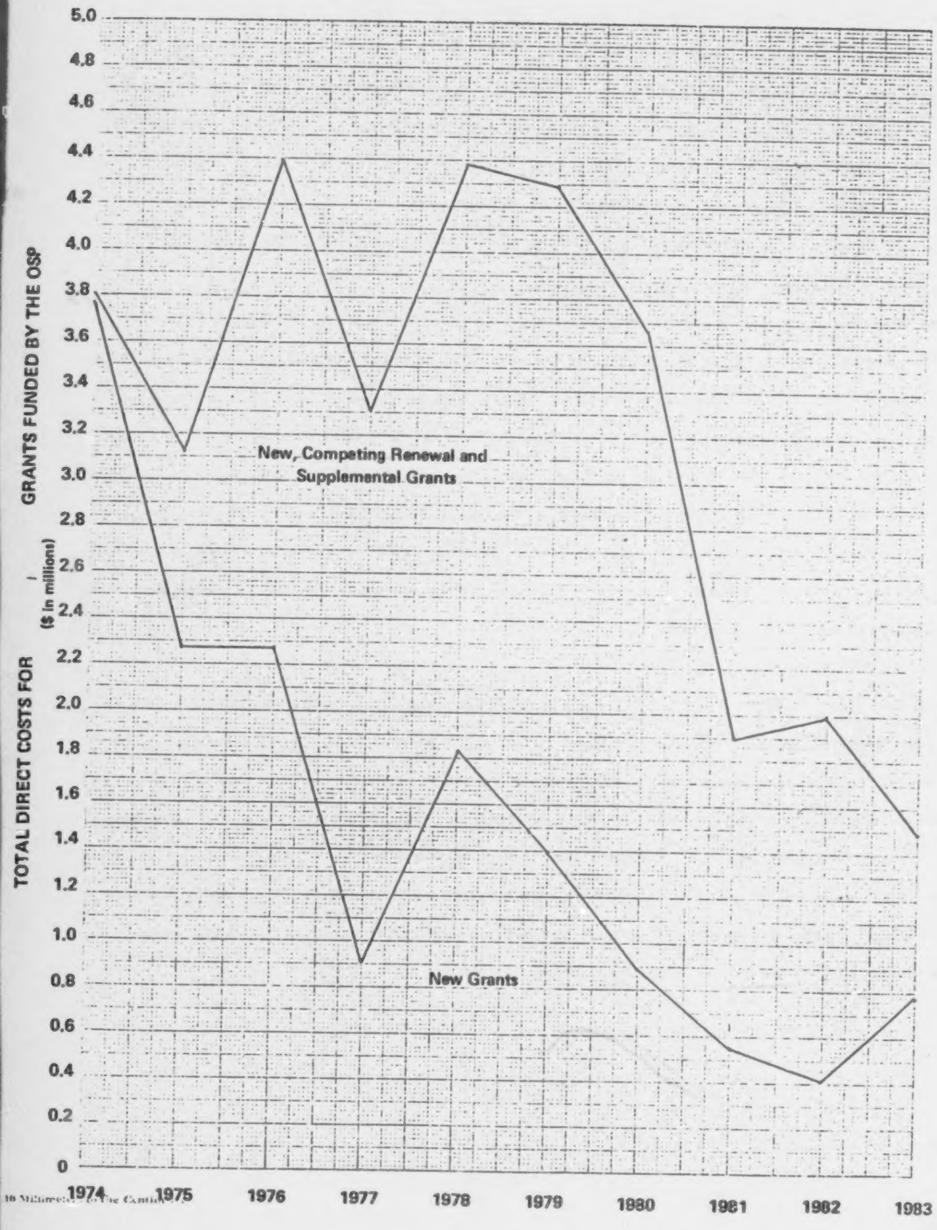
The National Cancer Advisory Board (NCAB) has supported the OSP as a valuable and productive program. According to the NCAB, the OSP represents one of the sterling examples of sucessful targeted research. The OSP Subcommittee of the NCAB has attempted to defend the OSP from elemination or reduction to insignificance. In response to the demand by NCI Administration for separation of program planning from review, the OSP Subcommitte of the NCAB agreed to changing review from OSP to R01 if an effective multidisciplinary R01 procedure could be developed which would maintain a mechanism for OSP implementation of its program plan. Instead, the NCI Administration abruptly suspended OSP review, transferring all grants from the OSP to single discipline R01 study sections with no mechanism for program implementation. This abrupt change was characterized by one NCAB member as a breach of contract by NCI staff with the Board. In the 1982 Senate appropriations report, the NCI was asked to continue funding the OSP for 1983 at the 1982 level pending hearings. Instead, as the accompanying figures show, R26 programs were reduced drastically. In the final OSP review, 27 grants were given fundable priority scores

(scores better than the overall NCI cut-off for grants). NCI staff recommended not funding these grants. Thus, instead of encouraging applications in these areas, they shut them off. Though the NCAB insisted that 24 of these grants be eventually funded, the message to applicants was evident. In the next review (OSP grants were reviewed by R01 groups), of just 33 grants reviewed for OSP research, only 3 were funded. This again sends a clear message to potential applicants in OSP targeted areas. These actions are destroying the entire momentum for cooperative research aimed at these targeted areas.

The OSP Subcommittee of the NCAB requested that a mechanism be developed for maintaining the four existing Organ Site Projects, adding a breast project and developing a coordinating center to initiate new programs or phase-out old ones as appropriate. The committee stated that a mechanism must be developed to allow rapid and successful program implementation for each of these projects. Instead, NCI issued an RFA for coalescing the five targeted programs into one generalized project. Though Working Cadres in each of the five areas would be maintained, no adequate mechanism was given for these Cadres to rapidly and successfuly implement their program plans. Though the NCAB requested, and the NCI Administration promised, a smooth transition from the old system to the new one, the NCI Administration recently released a list giving the new composition of Working Cadres. Many of the old members have been eleminated. These members have the most expertise in these areas and they have led the attempt to sustain the OSP. These actions again belie the words of the NCI Administration.

III. ACTIONS NEEDED

It is evident from the actions of the NCI Administration, from the evaluation by the OSP administrators, working groups and constituent scientists and from the OSP Subcommittee Chairmans own stated evaluation, that if the course of change proposed by the NCI Administration is not stayed, then the OSP will no longer be an effective program. It is also evident, from the lack of NCI Administration response to the 1982 Senate report language, that without strong and definitive Congressional action, the Administration of NCI will procede with the r plans, in spite of the NCAB opposition. We, therefore call for Congressional legislation maintaining a realistic budget for the R26 program, sustaining the existing Organ Site Projects and maintaining a review process with mechanisms for planning implementation.


TOTAL DIRECT COSTS FOR GRANTS FUNDED BY THE OSP
($ in millions)
5.0
4.8
4.6
4.4
4.2
4.0
3.8
3.6
3.4
3.2
3.0
2.8
2.6
2.4
2.2
2.0
1.8
1.6
1.4
1.2
1.0
0.8
0.6
0.4
0.2
0
1974
1975
1976
1977
1978
1979
1980
1981
1982
1983
New, Competing Renewal and Supplemental Grants
New Grants

TOTAL DIRECT COSTS FOR GRANTS FUNDED BY THE OSP*

Year	New Grants	New, Competing Renewal and Supplemental Grants
1974	$3,763,038	$3,807,408
1975	2,265,159	3,126,489
1976	2,267,523	4,393,042
1977	911,248	3,311,352
1978	1,830,528	4,380,318
1979	1,393,638	4,295,190
1980	885,064	3,668,101
1981	545,339	1,903,423
1982	412,832	2,025,812
1983**	777,463	1,486,268

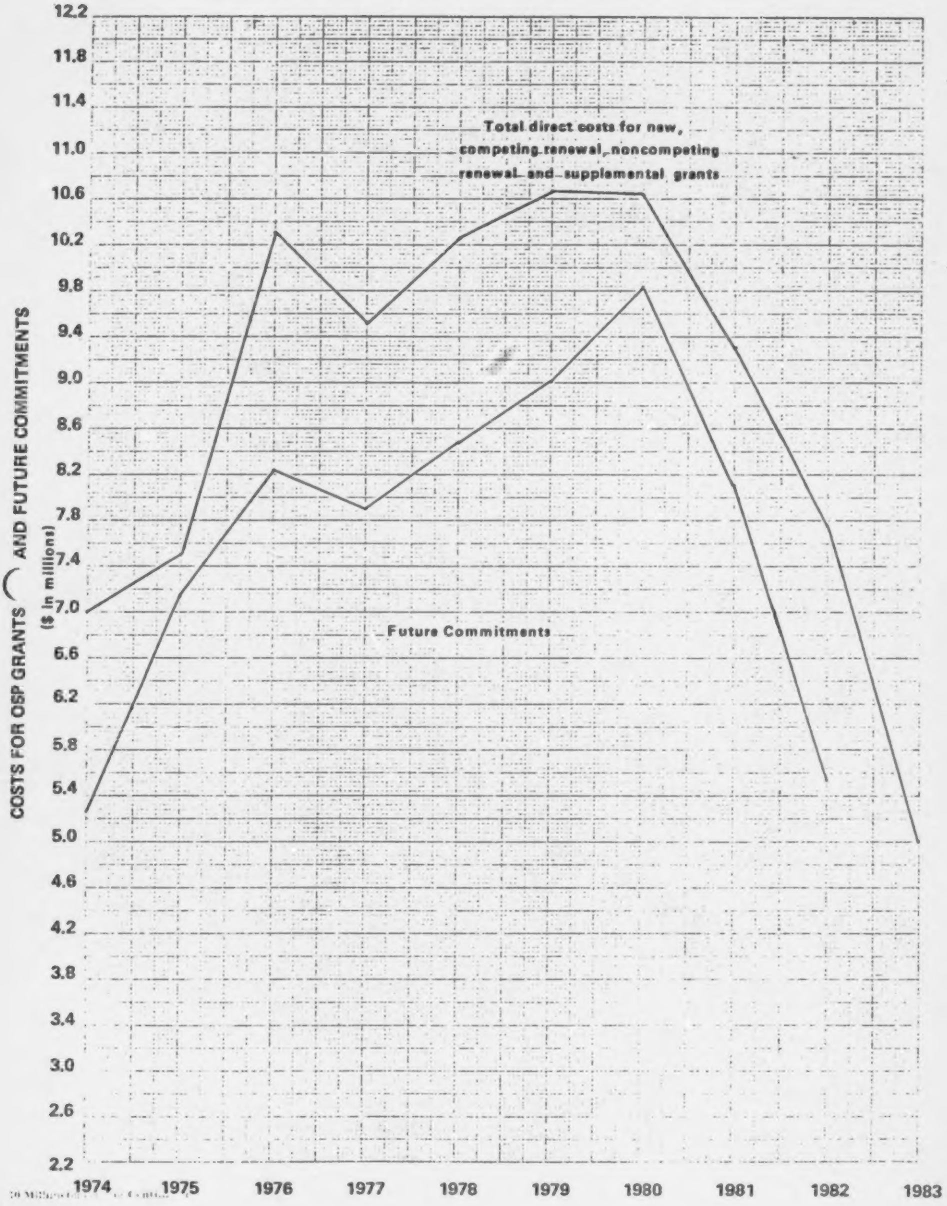
*All data were obtained from the Grants Financial and Data Analysis Branch of NCI.

**Data for 1983:

NEW GRANTS - $777[illegible].63 is the cost recommended for funding new grants as of April 13, 1983. This entire amount is for grants which were reviewed by OSP Working Cadres in FY 82, but which NCI refused to fund until NCAB action in FY 83. Thus far, no new grants, reviewed by NCI for OSP-related research, have been funded in FY 83. As there is one more review session in FY 83, a few grants referred to the OSP, but reviewed by Study Sections, may be recommended for funding.

COMPETNG RENEWALS - $708,805 is the cost recommended for funding competing renewals as of April 13, 1983. $505,005 of this is for grants which were reviewed by OSP Working Cadres in FY 82, but which NCI refused to fund until NCAB action in FY 83. The remaining $203,800 has been recommended for funding three grants referred to the OSP, but reviewed by Study Sections. Other competing renewals may be recommended for funding in the final review session of FY 83.

SUMMARY - Only 3 grants for $203,800 have been recommended for funding in FY 83 besides those which were recommended for funding in FY 82 but held over till FY 83.


COSTS FOR OSP GRANTS (AND FUTURE COMMITMENTS
($ in millions)
12.2
11.8
11.4
11.0
10.6
10.2
9.8
9.4
9.0
8.6
8.2
7.8
7.4
7.0
6.6
6.2
5.8
5.4
5.0
4.6
4.2
3.8
3.4
3.0
2.6
2.2
Total direct costs for new, competing renewal, noncompeting renewal and supplemental grants
Future Commitments
1974
1975
1976
1977
1978
1979
1980
1981
1982
1983

COSTS FOR OSP GRANTS AND FUTURE COMMITMENTS*

Year	Total direct costs for new, competing renewal, noncompeting renewal and supplemental grants	Total commitment for future years (Direct and Indirect)
1974	$7,060,636	$5,264,000
1975	7,515,714	7,162,000
1976	10,328,881	8,245,000
1977	9,533,420	7,894,000
1978	10,255,093	8,480,000
1979	10,665,366	9,107,000
1980	10,637,630	9,837,000
1981	9,304,906	8,177,000
1982	7,773,404	5,543,000
1983**	5,020,268	Not Available

*All data were obtained from the Grants Financial and Data Analysis Branch of NCI.

**DATA FOR FY 1983:

The method for deriving new and competing renewal costs for 1983 is discussed in the accompanying graph.

NON-COMPETING RENEWALS The estimated direct cost for noncompeting renewals in FY 83 is $3,534,000.

STATEMENT OF DR. WILLIAM E. POWERS, NATIONAL CANCER ADVISORY BOARD

Dr. Armand Hammer
c/o Ms. Eleanor Connors
Executive Assistant to the Chairman of the Board
Occidental International Corporation Suite 375
1747 Pennsylvania Avenue, N.W.
Washington, D.C. 20006

April 5, 1983

Dear Dr. Hammer:

Your letter to me with regard to the Organ Systems Program of the National Cancer Institute speaks to the words of the Directorate of the NCI, but not to the actions as I have observed them over the past several years.

The actions that prompt my concerns are as follows:

A. Reduction of funds for Organ Systems Program.

In the past several years the Organ Site Program has been reduced from $17.5 million yearly in 1980 to $13.5 million in 1982. This took place by a series of steps including a net reduction each time that the president recommended a rescission; the Organ Site Program budget was cut, and when the rescissions were restored, other programs were restored, but the money was still cut from the Organ System Program.

B. Cancellation of NCAB Subcommittee Meeting.

The Organ Site Program Subcommittee of the NCAB which was scheduled to meet in November was cancelled by a Division Director of the NCI after having been announed in the Federal Register and without consultation with me or the Chairman of the NCAB.

C. Subcommittee recommendations rewritten without subcommittee participation.

The recommendations prepared by the subcommittee for the Organ Site Program were edited and changed substantially by the NCI staff without the participation of the Organ Systems

Program Subcommittee, although we had submitted a revised draft that was modified to conform to the discussion held at the February 2 NCAB meeting. This draft was submitted to a Division Director of NCI in a completed form on February 3, after discussion with Dr. Carter, Chairman of NCAB.

D. Inappropriate review of Organ Site Program Grants.

Although the subcommittee had been assured in committee hearings by the appropriate NCI Division Director that the review process of multidisciplinary applications would include special ad hoc review when appropriate; in fact, this did not occur for any of the applications.

E. Concern about phase out of headquarters.

We are faced with apparent phase out of at least one of the Organ Site Program headquarters on November 30, 1983. This will probably result in a suspension of activity in that organ site during the transition period until March 4, 1984 when the new award will be made. This, in effect, will reduce the momentum for the pancreatic program. Presumably NCI staff can address this problem by administrative extension.

F. Failure to involve the Organ System Program working groups in major new projects.

For example, a major new program on prevention of breast cancer by diet was presented to the Breast Cancer Task Force after concept review by the Division Board of Scientific Concillors and after the "Request for Applications" had been developed and announced in the "Cancer Letter".

As you are aware, I have been a member of the NCAB Subcommittee for Organ Site Programs since the time of my first appointment to the NCAB in 1974. Thus, I have had an opportunity to observe the changes that have taken place. My great concern is that the NCI Directorate seems intent on reducing the activities of the outside participants of the Organ Systems Program while preserving a very much weakened program.

This is of particular concern to me since the present administration has proposed decentralization of government control and administration whenever possible. The Organ Site Programs which have operated mainly outside of the NCI have succeeded in recruiting scientists and practicing physicians into collaborative research efforts in topics where little research had existed and are thus an excellent example of decentralized research administration. The Organ Site Programs have been particularly productive in bringing surgeons into the research programs (3 programs are headed by surgeons), a need not previously met successfully by other activites of the National Cancer Program. The programs have been successful in stimulating needed research into several of the diseases that represent significant causes of death due to cancer.

In these concerns, I do not propose malice from the NCI Directorate, but rather a major difference in philosophy. I believe a significant part of program planning and communication can be accomplished best by the several hundred investigators who have been contributing time and effort to this program. They, in turn, feel they cannot have impact without some participatory involvement rather than being informed ex post facto.

To this end, I hope you and your colleagues will consider these concerns and join with me in efforts to have a strong well funded Organ System Program with continued significant participation and leadership from physicians, surgeons and scientists who are outside the NCI. Such an expanded program (to include additional organ systems recommended by the NCAB) will require extra funding and action by Congress.

I join you in respect for the tremendous accomplishments over the last years due in large part to the dedicated staff of the NCI.

STATEMENT OF JORDAN U. GUTTERMAN, M.D., PROFESSOR OF MEDICINE, THE UNIVERSITY OF TEXAS SYSTEM CANCER CENTER, M.D. ANDERSON HOSPITAL AND TUMOR INSTITUTE

Senator WEICKER. At this time the chairman will turn the chair over to my good friend, the Senator from Wisconsin, Senator Proxmire, and the same rules apply; he's even tougher than I am as far as making the machine work.

Senator PROXMIRE [presiding]. Our next witness is Dr. Jordan Gutterman, profesor of medicine, University of Texas.

Is Dr. Gutterman here?

It's an honor to have you, sir. Proceed in your own way according to the rules.

Dr. GUTTERMAN. Thank you, Mr. Chairman. I'm a professor of medicine at the University of Texas System Cancer Center in Houston. I'm a board-certified internist and oncolgist and I've been involved the last 12 years in the clinical and laboratory investigation of biological agents for the treatment of human cancer.

During the last 5½ years I have particularly focused on a prototype of biological treatment of cancer, the use of the interferons.

Because of the National Cancer Act passed in 1971, tremendous progress has been made in the last decade on our understanding of the cancer process. And the fruits of that work now are highly successful in the introduction of new technologies such as recombinant DNA, monoclonal antibodies and our understanding of cancer genes and even of the discovery of a virus that causes a specific form of a human cancer.

Because of this revolution in cancer research, we are beginning to see the payoff in terms of clinical application of some of these new concepts, and I'd like to briefly discuss with you the application of one of those substances, the interferons, in the treatment of cancer.

The interferons represent a new concept, the use of biological response modifiers in the treatment of cancer. These substances were discovered in 1957 as antiviral substances, but today we know that these materials also regulate the growth of cells in the body.

There is now substantial evidence that one of these forms of interferon has potent anticancer activity in several human malignancies.

During the last year, for example, dramatic new advances with leukocyte interferon had been achieved in patients with advanced kidney cancer.

This tumor, which accounts for 17,000 new cases per year and 8,000 deaths, is very difficult to treat when it spreads or metastasizes. We have found that approximately one out of three patients can achieve either a partial or even complete disappearance of the tumor with interferon alone.

Some of these patients have had complete remissions lasting more than 1 year. This is dramatic news for patients with kidney cancer, and the work has now been confirmed under the auspices and support of the American Cancer Society, as well as scientists at UCLA and at Yale.

Another breakthrough has come with the use of these natural interferons and the treatment of chronic leukemia, and over 80 percent of patients can have control over their disease.

Progress has also been made in viral diseases, including viral growth of the larynx called laryngeal papilloma, and more recently progress has been made in a highly lethal cancer, malignant melanoma.

The importance of these studies, Mr. Chairman, is that the interferons open up a new way of thinking about the cancer problem, that is, the use of natural substances, not to supplant the use of radiation or chemotherapy in the treatment of cancer, but to add to our therapeutic approach, because 60 percent of cancer patients still die and over 1,000 patients die every day in this country due to this dreaded disease.

And there are several important approaches which must be investigated in this area, including other lymphal kinds, pure monoclonal antibodies, and so forth.

Mr. Chairman, you and the members of the Senate have the opportunity that could eventually save the lives of hundreds of thousands of people in the United States and over the world.

Cancer is very democratic; one out of every four in this room will develop cancer and one out of every five will eventually die of this terrible disease.

New insights into the development of cancer have occurred with our understanding of cancer genes and the recent discovery of, as I said earlier, of a virus that causes one form of human leukemia, and indeed there may be other viruses that are the causative agent in several forms of human cancer.

Cancer is a part of living and we must have a defense against this. As you know, the Federal Government spends more money on national defense in 2 days than it spends during 1 entire year in cancer research.

I support the American Cancer Society's figure of increasing our cancer budget to $1,500,000,000. That money could be well spent.

The terms of economic and human suffering is devastating. We have the progress now, and I think over the next decade we should be able to dramatically decrease the death rate with our new understandings of causations of cancer.

Thank you.

PREPARED STATEMENT

Senator PROXMIRE. Thank you very much, Dr. Gutterman. We very much appreciate that statement.

[The statement follows:]

STATEMENT OF JORDAN U. GUTTERMAN

MR. CHAIRMAN: I am a professor of medicine at the University of Texas System Cancer Center, M.D. Anderson Hospital and Tumor Institute, Houston, Texas. I am a board certified internist and oncologist with subspecialty certification in Hematology. I have been involved for the last 12 years in the clinical and laboratory investigation of biological and chemotherapeutic agents for the treatment of human cancer. During the last 5 1/2 years, I have focused my clinical and laboratory research on the antiviral and antitumor natural substance, interferon.

Interferon was discovered in 1957 as a natural antiviral, hormone-like protein that is produced by most human cells. Interferon has been traced back in the evolutionary scale to fish and amphibians. Today, it is believed that interferon is the body's first line of defense against viral infections and possibly some malignant tumors. Interferon's ability to slow down or stop the growth of cancer cells was discovered in 1962. Over the last 21 years, a tremendous amount of biological and chemical knowledge on interferon has been described in the scientific literature. Interferon has been shown to have potent antitumor effects in a variety of animal tumor models.

Since interferon works primarily in the species of origin, until recently we had to use interferon from human sources in order to treat human disease. There are three primary types of interferon in the body. One is called leukocyte (alpha) interferon which is produced by white blood cells. Another major type of interferon is called fibroblast (beta) which is produced by most of the tissue cells of the body. A third type of interferon is called immune (gamma) interferon. This interferon is 10-50 times more potent than the other interferons and potentiates the antiviral and anticancer activity of leukocyte and fibroblast interferon.

There is now substantial evidence that leukocyte interferon has anticancer activity in several malignancies including osteogenic sarcoma (bone cancer), advanced breast cancer, advanced kidney cancers, multiple myeloma (a tumor of the antibody-producing cells of the bone marrow), malignant lymphoma, nasopharyngeal tumors, acute leukemia and chronic leukemia. Thus, 25-80% of these patients achieve remissions of their tumors with leukocyte interferon therapy.

During the last year, dramatic new advances with leukocyte interferon have been achieved in patients with advanced kidney cancer (renal cell carcinoma). This tumor, which accounts for 17,000 new cases of cancer per year and 8,000, deaths is untreatable when it spreads or metastasizes. We have found that one out of three patients achieve remissions with leukocyte interferon alone. Some of these patients have had complete remissions now for more than one year. This is dramatic news for patients with kidney cancer and the work has been confirmed by the American Cancer Society, scientists at UCLA and elsewhere. Another dramatic breakthrough occurred with interferon in the treatment of a chronic leukemia called chronic myelogenous leukemia. Over 80% of patients have achieved remission of their disease with interferon. This is not to say that the patients are cured. What we now have to find out is whether interferon can prevent the transition from the chronic to the acute, highly lethal form of the disease. These are some of the examples, Mr. Chairman, of dramatic breakthroughs that have come with interferon.

It is imperative to point out that these initial studies started in Sweden in the mid 70's and in the United States in early 1978, were all carried out with small amounts of impure (less than 1% pure) interferon. The original work at the Karolinska Institute in Sweden, at Stanford University in Palo Alto, and at the University of Texas System Cancer Center, M.D. Anderson Hospital in Houston, has now been confirmed in limited trials conducted since 1979 by the American Cancer Society and more recently by the National Cancer Institute. My co-workers and I at M.D. Anderson have carried out limited clinical trials in three major killers; advanced metastatic colorectal cancer, prostate cancer and ovarian cancer. Although the response rates have not been high, we have observed partial remissions in 25% of 30 patients with these malignant tumors.

In addition to human malignancies, Dr. Merigan has described the important work of interferons in viral diseases. Included in viral diseases are the laryngeal papillomas, wart-like growths caused by a human virus, on the vocal cords of young children. We have treated 14 patients at M.D. Anderson; 11 additional patients were treated at the University of Iowa. The majority of these patients have experienced dramatic and complete regression of these wart-like growths. The treatment avoids anesthesia and extensive surgery which is the usual treatment for this disease.

There has been much written during the last 2 years in the lay press saying that the clinical work with interferon in cancer patients has been "disappointing". These statements come from individuals who do not understand the clinical investigation of interferon. In the press, the results with the impure leukocyte interferon are often compared to multiple drug, toxic chemotherapy regimens which have been studied the last 20 years. What is important is that the impure interferon causes significant tumor regression in many tumors. We have not had sufficient tumor regression in many tumors. We have not had sufficient material to adequately test various doses, schedules, etc. No one would deny now that interferon does have the important capacity to induce remissions. That alone is a major finding. Interferon opens up a new form of cancer treatment with biological agents which are less toxic than conventional approaches. There is no nausea, vomiting, diarrhea or the other drastic side effects of chemotherapy.

What has happened in the interferon field since I last testified before your committee? Mr. Chairman, many remarkable developments have occurred. I predicted three years ago that it would be 3-5 years until a pure, biosynthetic form of interferon was available for clinical investigation. I was wrong. In January 1980, Dr. Charles Weissmann from Zurich, Switzerland announced interferon had been successfully cloned in bacteria. That is, E. coli bacteria were able to manufacture leukocyte interferon after insertion of the interferon gene (DNA). With the introduction of pure monoclonal antibodies, Genentech and the Roche Institute of Molecular Biology were able to purify leukocyte interferon from bacteria. Through the remarkable technology of DNA research which the Congress has supported for the last 25 years, we know that there are at least ten to twelve different species of leukocyte interferon. The precise roles of these species in clinical medicine are not known.

On the 15th of January 1981, we treated the first patient in the world with pure, synthetic leukocyte interferon manufactured through the recombinant DNA technique. What have been the clinical results with the pure recombinant leukocyte interferon? We carried out a study of 16 patients in conjunction with Dr. Merigan and his group at Stanford. The initial study was done with so-called clone A or alpha 2. We have learned that the interferon molecule is responsible for the induction of the side effects noted with the crude preparations, namely fever, fatigue, malaise and most of the side effects that you and I experience with viral infections. In addition, the pure interferon molecule seems to reproduce the other clinical effects of the crude preparations, namely the regression of metastatic tumor. Thus, seven of 16 patients experienced regression of metastatic tumor during this initial pharmacological study. Subsequent Phase I studies carried out by numerous institutes in conjunction with Hoffmann-La Roche have shown that at least one out of four patients with very advanced refractory incurable cancers have experienced similar remissions. Phase II efficacy studies are now being conducted throughout the world. Similar studies are now being conducted with the second leukocyte interferon clone, the so-called clone D or alpha I.

Fibroblast interferon has also been successfully produced in bacteria during the last several months. Studies are now underway to purify fibroblast interferon. Clincal studies with pure fibroblast interferon produced from bacteria started recently. This, Mr. Chairman, is an absolutely remarkable story, for we now are very close to having ample supplies of interferon to investigate the interferons in all the 20 major cancers. Once we can determine which of these interferons work for different cancers, we can begin treating cancer patients before the tumor has metastasized.

Immune interferon is a more potent anticancer drug than either leukocyte or fibroblast interferon. Immune interferon potentiates the antiviral and antitumor activity of both leukocyte and fibroblast interferon. It is expensive to produce this material. After several frustrating years of waiting for the stabilization and partial purification of immune (gamma) interferon, we initiated the first FDA approved clinical study on the 9th of February, 1982. This material still is in extremely short supply, but I can say to you that the material is stable, appears to be absorbed in the blood stream and has potent biological activity. Of great interest is that the first responses we have had with the natural gamma interferon have been in patients with kidney cancer. We are quite excited about combining two forms of interferon in the treatment of this disease. Recently, immune interferon was successfully synthesized in bacteria by Genentech. The synthetic immune interferon will be ready for clinical studies within a month.

There is a need for large funds to further laboratory and clinical investigation of the interferons. We desperately need laboratory techniques to determine which of the many species of leukocyte and fibroblast interferon are indicated to treat individual cancer patients. There are significant leads which must be followed in the laboratory. For example, there are receptors for the different interferons on cancer cells. We need tests to determine which receptors are present for which types of interferon. The use of pure interferon and monoclonal antibodies are essential in this work.

How can we evaluate the multiple forms of interferon, separately, and in combination with each other, as well as in combination with chemotherapy in the 20 major cancers? How can we eventually find out if the interferons can prevent cancer? Mr. Chairman, in my estimation we must ask the cooperative cancer chemotherapy groups to carry out these studies nation-wide. These groups are strategically located around the country so that patients in virtually every state could have access to these important agents.

Interferon opens up a new concept of cancer treatment and research (Biological Response Modifiers). There are several important approaches which must be investigated including the interferons, other lymphokines, monoclonal antibodies, tumor necrosis factor, and so forth. Monoclonal antibodies are pure substances that can be targeted to kill cancer cells without harming normal cells. Monoclonal antibodies should be important diagnostic and therapeutic reagents for cancer in the near future. There is little doubt in my mind that with the proper financial support we will soon have an array of biological agents which are essentially nontoxic and which could be targeted to the tumor cells with few or no detrimental effects upon the cancer patient. Mr. Chairman, you and the members of the U.S. Senate have the opportunity that could eventually save the lives of hundreds of thousands of people in the U.S. and all over the world. Let us not waste any more time with this effort. The 420,000 patients who die every year cannot wait any longer for more progress. We are all aware of the economic problems of this country. But cancer is democratic. One out of every four people in this room will develop cancer in their lifetime and one out of every five will eventually die of this terrible disease. We are beginning to understand what causes a cell to become malignant. New insights into the evolution of cancer has occurred with our understanding of oncogenes or cancer genes. We are learning now about the products of these genes, that is proteins, which can convert or transform a normal cell into a cancer cell. Of great interest is the fact that the protein product of one of the cancer genes, the sarcoma gene, can be inhibited by interferon.

We must not lose the momentum of the major achievements that have occurred during the last several years.

Mr. Chairman, we urge you to appropriate the ncessary funds to allow us to manufacture immune interferon, to study the many species of pure leukocyte and fibroblast interferon, and to evaluate pre-clinical methods to select the appropriate interferons for individual cancer patients. I think it is imperative that at least 100 million dollars be earmarked for the whole area of biological response modifiers in cancer, of which 50 million should be directed toward interferon research in cancer. We need your help in moving us toward our goals for successful treatment of cancer with natural nontoxic drugs. THE FEDERAL GOVERNMENT SPENDS MORE MONEY ON NATIONAL DEFENSE IN TWO DAYS THAN IT SPENDS DURING ONE ENTIRE YEAR ON CANCER RESEARCH. THE COST TO SOCIETY BY THIS DREAD DISEASE IN TERMS OF HUMAN SUFFERING AS WELL AS IN ECONOMIC TERMS, DEMANDS A MORE JUST BALANCE IN GOVERNMENT APPROPRIATIONS. YOU REPRESENT THE PEOPLE, AND THE CITIZENS OF THIS COUNTRY WANT MORE MONEY APPROPRIATED TO ERADICATE THIS ENEMY FROM OUR LAND.

In addition to these exciting results with interferon, increased understanding of the malignant process has come from basic research laboratories. It is extraordinary how much more we understand about the cancer process than we did three years ago. One of the most exciting new breakthroughs in basic research has been the isolation of a virus that appears to be responsible for a specific human cancer, namely T cell lymphoma or leukemia. This work carried out by Dr. Gallo and his associates at the National Cancer Institute is of paramount importance. In 1980 Dr. Gallo detected a type C cancer virus in cells from a patient with T cell leukemia. This virus has been designated human T leukemia virus or HTLV. In the past few months progress has been rapid and dramatic. Another virus has been reported from a second case of cutaneous, adult T cell leukemia. In addition, two further isolates of HTLV have been made in the United States. Exciting new information relevant to the possible regional significance of HTLV in adult T cell leukemia has now emerged from Japan. For the first time it appears that a human virus has solidly been demonstrated to cause a human cancer. If this proves to be the case, this virus will join the EB virus, which is associated with Burkitt's lymphoma and nasopharyngeal carcinoma and hepatitis B virus, which is implicated in the cause of primary liver cancer. Extensive funds are needed to carry out epidemiological studies throughout this country and the world to further substantiate the association of this virus in cancer. We now have the potential for developing a viral vaccine that could prevent this particular cancer. Viruses for other types of cancers will probably be found. This work could serve as an important prototype for the development of other vaccines for cancer. We urge the congress to appropriate 100 million dollars to carry out these important epidemiological, virological and clinical studies.

STATEMENT OF DR. ROBERT HUTTER, CHAIRMAN, PUBLIC ISSUES COMMITTEE, AMERICAN CANCER SOCIETY

Senator PROXMIRE. Dr. Hutter, chairman, public issues committee, American Cancer Society.

Is Dr. Hutter here?

Dr. HUTTER. Mr. Chairman and members of the committee, I am delighted to be here today on behalf of the 2,500,000 volunteers of the American Cancer Society.

Our mission is of vital importance to the health of the Nation.

We're here to present to you a request for $1,500,000,000 for the National Cancer Institute. This amount would sustain continuing programs and help restore the cuts in the drug development program, the cuts in the organ site program, the cuts in the cancer centers program, the 4-percent cuts in research grants and contracts which have occurred each year for the last 3 years.

I'd like to remind the members of the committee that the American Cancer Society, as a matter of policy, accepts no Federal funds and, therefore, receives no direct benefit as a result of this committee's decisions.

Our commitment to the American people, as physicians, scientists, and lay people is the ultimate eradication of cancer.

In this year alone, cancer will strike 855,000 Americans and kill 440,000. In the late 1970's, cancer cost this Nation over $9 billion in direct medical care costs. And in addition, $13 to $17 billion annually in lost wages and liquidated assets. And these figures are staggering.

Nevertheless, despite the problems, there are encouraging signs. We're virtually on the threshold of truly understanding the biological mechanisms whereby a cancer cell is converted into cancer from a normal cell—how cancer genes, that is, oncogenes—transform normal cells to cancer.

If we can extrapolate from laboratory experiments the mechanism to control cancerous genes in people, we may then be able to prevent clinical life-threatening cancers in susceptible people and possibly even reverse the cancerous process after it is clinically manifest.

We have achieved a cure rate for cancer that's rapidly approaching 50 percent. This is the good news, the news for which the members of this distinguished body deserve a large share of the credit.

However, we're deeply disturbed by the recent trends in Federal funding of cancer programs. We perceive an attitude in Washington, whether intended or not, that suggests an attenuation of the Government commitment to the national cancer program.

During the last 3 years, NCI funding increased only 2.8 percent, the lowest increment of any of the institutes, while the level of increase for the next lowest was 16.1 percent, almost six times greater than the NCI.

These figures are ominous signals to us that Congress and the administration may be retreating from the commitment to the American people of this great Nation to eliminate cancer.

Our current national economic difficulties must be met with a judgment to ration dollars where necessary, the compassion to provide the cure for more cancer victims today and the wisdom to invest in research now so that we can have a world without cancer in the future.

The American Cancer Society believes that you understand. We have faith in your wisdom, and trust in your judgment. We thank you for all that you have done and for all that you will continue to do.

[The statement follows:]

STATEMENT OF DR. ROBERT HUTTER

This year the American Cancer Society, the world's largest voluntary health agency with over 2-1/2 million volunteers, will spend $58 million on research grants and projects. None of the that money comes from either federal or state governments. At that level of funding of grants for research, the ACS will be able to fund about one of ten of new approved grant applications. We are proud of the accomplishments of this program and frustrated by the fact that we can fund so few scientifically meritorious projects.

This frustration makes us perhaps uniquely qualified to testify on the National Cancer Institute Appropriation level. We know firsthand how many worthwhile, exciting research projects are underway in the cancer field. We also know, firsthand, how it feels to say no to the majority of those who submit projects and to hope that somehow those investigators will find the necessary funds elsewhere, realizing that in all likelihood they will not. The people at the National Cancer Institute also know the frustration, the sadness, the fear that the one you turned down for whatever reason might be the one that could have made the difference for thousands of people who will die of some form of cancer in the coming years.

This year NCI will have to turn down approximately 1,870 approved applications of the 2,600 they will receive. They will be able to fund only approximately 800 grants even under the new OMB directive.

We are, therefore, herein presenting the ACS position recently passed by our National Board of Directors calling for a funding level of $1.5 billion for NCI. We are asking for that amount because we believe that that is the funding level necessary to restore the momentum of the cancer program, to bring present programs back to earlier vigor and to permit the new and innovative research begun in recent years to come to successful fruition. Because of the costs of cancer, costs that amount to over $25 billion a year, the money is clearly an investment in our future.

We at the American Cancer Society understand that these are difficult times and that budget cutting is necessary. We also understand that everyone you hear from in the public sector is saying "yes, cut the budget, but not my program." We understand the enormity of your tasks and we hope we can make the choices a little more understandable to you.

We all know the numbers. In 1983 440,000 people will die of cancer, one American every 72 seconds. 54 million people now alive will get cancer. It will cost our nation over $9 billion in hospital costs and medical care expenditures, and between $13 and $17 billion in lost wages and forced liquidation of assets. The average cost for the individual to die of cancer today is about $20,000. Those are the numbers you hear all the time.

Now we want to tell you the numbers that we care about and for which we believe you bear an enormous responsibility and in which you should take considerable pride. There are two million people alive today who have had cancer and survived five or more years. (Most of the two million can be considered cured.) There are over three million people alive today who have a history of cancer. We have achieved a cure rate for cancer that is fast approaching 50% and if you include easily treated skin cancers and some other similar cancers, the cure rate jumps to over 65%.

In 1970 the survival rate of children with cancer was about 39%. Now over 54% of children are surviving cancer. Osteogenic Sarcoma survival rates have increased from about 26% in 1970 to about 41% now. Non-Hodgkin's Lymphoma from about 18% in 1960 to about 38% now. Early forms of Wilm's Tumor had a cure rate of over 72%, Ewing's Sarcoma - 42% and even childhood brain tumors have jumped from 45% in 1970 to approximately 51% now. These are remarkable strides representing thousands of lives.

Breast cancer is a disease that will kill almost 40,000 women this year, a disease that one in 11 American women will get in their lifetime. We have had static survival rates for breast cancer for many years. These rates have begun to improve and even more dramatic improvements are expected over the next five to ten years when survival rates for women who have had early diagnosis and others who have taken chemotherapy as part of their treatment become clearer. These dramatic survival rates for breast cancer, from 63% in 1960 to 72% now, are manifesting at a time when physicians are finding they are able to do less radical surgery on many patients and when new techniques are being developed for reconstruction. This is clearly a time when there is good news for the breast cancer patient.

Cervical cancer has a 90% or better cure rate since the discovery of the pap smear, mainly because doctors are finding the disease when it is still at a stage where successful treatment is possible, something that was not true several years ago.

Perhaps the most important understanding in all of cancer research is the fact that we do not develop cancer because we are born people. Cancer occurs, for the most part, because of something we do, we eat, we drink, we smoke, to some extent where we live.

This is a blessing. It means we are beginning to be able to identify those things to which we are exposed. We have enough information now to prevent well over 50% of cancers. One of the tasks we now have, both at the NCI and with the American Cancer Society, is to get people to use this information. It is information that we have today that we could not have told this Committee about just eight or nine years ago.

The Congress has made funds available over the last couple of years to study such naturally occurring compounds as Interferon. Interferon is every bit as exciting as it used to be. A year or two ago we would have told you that we had one Interferon, that we had to produce it outside of this country, and that it cost about $30,000 to treat a single patient. Now we can tell you that there are about 14 different Interferons, all of which are under test or need to be tested, and that we are producing it abundantly in this country. We have bucketsful now instead of a thimbleful, as we had a year ago, and it costs about $200 to $300 to treat a patient. This is tremendous progress, all of which again was done either through the voluntary sector or through the National Cancer Institute.

We are looking to other natural products that can be tailor-made to treat particular cancers, sort of intelligent antibodies. Monoclonal and hybradomas antibodies are simply antibodies that act like a rifle instead of a shotgun when you treat the patient. They go right to the tumor and consequently have far less side activities. This is a whole new era of drug development that we would not have thought about three or four years ago. Part of the funds that we are asking through your authorization would go toward that kind of drug development program, sorely needed and inadequately funded at the present time.

There is this whole new phenomenon called oncogenes. As you know, we are born with chromosomes. We each have 46. On those chromosomes are genes that code for the length and color of our hair, even our personality, the length of our fingers, the length of our nose and so forth.

We also have genes that say make tissue, make blood cells, make bone marrow. After we are babies, perhaps even in utero, when the job of making bone marrow and blood and tissue is over, these genes turn off. We do not need them anymore. But we never lose them. We now understand that in one in three Americans later in life those genes switch on again, but when they switch on they do so in a random fashion. They build muscle or blood cells under no control. By definition this is what we call cancer.

So for the first time in the history of cancer research, we can now ask two questions: What turns them on? Is it viruses? Is it asbestos? Is it the water we are drinking? Is it sunlight?

And finally, the big question that we are addressing in all of cancer research is: How do we turn those genes back off?

We have already done it in animal systems. If we can do it in people, we have got a unique approach not only to prevention of cancer, but in the treatment of existing cancer patients. By turning oncogenes in existing cancer cells off, we can get those cells to revert back to normal.

Much of this good news and many other important breakthroughs have come about as a result of the care, interest and money provided by the federal government. Truly, the progress in cancer research is a testament to government and science working together to make life better for our citizens.

The 1970's were the golden years, the years of the building of a cancer research and treatment network second to none in the world, the years of extraordinary breakthroughs in treatment and prevention, the years of momentum, the years when young scientists rushed to get into the cancer field because they knew that was where the action was. To many of us who witnessed what the infusion of government money and interest could do, these last few years have, in comparison, been years of sad winding down.

We in the cancer community feel a loss of momentum. We feel the loss of interest by many bright, young researchers who do not believe there will be sufficient interest or funds in cancer research for them to work on their best and most interesting ideas. We feel the frustration of out-of-date equipment in our cancer laboratories funded by the federal government.

NCI information shows the Cancer Center's program improves treatment within a radius of 300 miles around each of the 63 Centers because of improved physician awareness and training and offers of support services. Our Cancer Centers and participating community hospitals are the essential element in any regional cancer control network. They are the best equipped facilities for specialized cancer treatment such as bone marrow transplants and new chemotherapy regimens or for interferon trials which are also supported by the National Cancer Institute and the Cancer Society.

We are distressed by cuts in the organ site program which has demonstrated the effectiveness of chemotherapy in advanced regionalized prostate cancer, the value of preoperative radiation in bladder cancer, and has lead to the discovery of antibodies which may be found in increased amounts in the blood of patients with localized pancreatic cancer. If this proves valid, it may lead to earlier detection and possible cure.

We have suffered cuts in the drug development program which gave us chemotherapeutic agents that are responsible for dramatically increased survival rates for cancer patients. The drug development program has been cut by 30% in the last couple of years. Overall, reserch grants and contracts have taken yearly 4% cuts since 1980 translating into over 50 grants that could not be funded last year.

We at ACS are concerned because we know that despite the good news which we periodically bring to you here on Capitol Hill, cancer still kills. Despite the progress made in childhood cancer, cancer is still the number one disease killer of our young children. Breast cancer still kills many of its victims.

The American Cancer Society appreciates the Chairman's interest in cancer research and the interest of the members of this Committee. However we are well aware that if the trend in funding increases had continued at the rate that existed during the early '70's, the Chairman today would be offering a bill with a $1.6 billion appropriation and no one would think very much of it. We are asking for $1.5 billion.

What, you might ask, would the NCI do with that money. It could restore the organ site and cancer centers programs to full vigor; restore and perhaps increase the drug development program so that the all-important work in chemotherapy could continue at acceptable levels; enable research laboratories to operate with the best equipment available; continue to attract and train the best and the brightest researchers; greatly expand the work being done in viral oncology and genetic engineering.

Attached are two bar graphs which show the percentage increase of funding for NCI as compared with other NIH Institutes. It is clear that the NCI percentage increase does not come close to the inflation level and that recent appropriations for NCI (two years of budget cuts and one year with an increase of less than 5%) seem to indicate a lack of interest on the part of the federal government in the cancer program.

While the cancer program will be severely restricted, it will not die if appropriation levels continue as they have in recent years or even the budget recommendation of the President succeeds in this Congress. We work every day with researchers who will do their best to continue their work in spite of the hardships they must endure so long as some funding is available. We know their dedication.

But, the death of the cancer program is not the issue. The life, the vitality and the health of our people are the issues. Cancer is a devastating disease. It is the most feared disease by far in our country. It is associated in the minds of our citizens with pain and with long and difficult death and in all too many instances that is the truth. It is an unsual disease, a disease of the basic body components. Those are the facts we deal with every day in the cancer community. It takes a special kind of doctor to be an oncologist. We are privileged to know many.

Yet, ten years from now, probably far less, we will be able to identify the 25% of the population likely to get 80% or more of cancers; we will know enough about what it is that triggers cell mutation and transformation to stop it and thereby prevent cancer, we may well have vaccines that also prevent cancers. By the year 2000 cancer may not be the most feared disease in our nation. It may not be the number one disease killer of our children. It may not attack one in three of our citizens and have a devastating impact on 2 out of 3 of our families.

That is the reality of those of us in the cancer community. This could be the most exciting time ever in the history of cancer research. This could be the time when we begin to win the many-fronted war we have been fighting for so long. Or this could be the time when we postpone that victory for decades.

Our children and their children will reap the benefits or pay the price. It is up to us and our colleagues. We accept that responsibility. However, we know very well that it is also up to you and your colleagues. We are once again asking you to continue to accept this responsibility, to take pride in the program you initiated in 1971 -- the most visible, emotional, important, and successful health program in the biomedical history of any nation. Gentlemen, help us to help all of you and your constituents faced with the pervasiveness of this disease and its consequences so that we may not reverse years of progress and leave in our wake so much unnecessary suffering that it will be as if we had indeed lost a major war. Not only can we not afford the financial consequences of surrendering in this war, we cannot countenance the moral consequences of such a disastrous surrender.

STATEMENT OF DR. PHILIP S. SCHEIN, PRESIDENT-ELECT, AMERICAN SOCIETY OF CLINICAL ONCOLOGY

Senator PROXMIRE. Our next witness is Dr. Philip Schein, president-elect, American Society of Clinical Oncology.

Dr. SCHEIN. Senator Proxmire, I'm Dr. Philip Schein, professor of medicine and pharmacology at Georgetown University and director of the Vincent T. Lombardi Cancer Research Center at that institution.

Senator PROXMIRE. That rings a bell.

Dr. SCHEIN. I hope it does.

Senator PROXMIRE. Mr. Lombardi is a great hero in Wisconsin.

Dr. SCHEIN. A hero for us as well.

I appear before you representing the American Society of Clinical Oncology, an organization consisting of almost 4,000 clinical cancer specialists through the United States.

The importance of cancer as a health problem in the United States is well appreciated. It is estimated that during the course of 1983, as you heard, some 850,000 Americans will be diagnosed as having a new cancer and, of these, some 440,000 can be expected to die of their disease, with unmeasurable human suffering.

Our concern, deeply shared by many others in the scientific community, is that the previous commitments of Congress and the executive branch of Government to the prevention and treatment of cancer has diminished, despite the tangible progress that has been made in dealing with this important societal problem.

The National Cancer Institute, in carrying out the National Cancer Act of 1971, established the most effective apparatus for cancer care and research ever developed. In turn, the associated medical centers and scientists have responded with substantial commitments of their precious resources, of personnel, space, and developmental funds to this common goal.

Through the national resources of the cancer centers program, the cooperative cancer clinical investigative groups, and the cancer control program, the National Cancer Institute has insured that new successful treatments for cancer have rapid and widespread application as community standards of treatment.

The national cancer program has already begun to realize its objectives. Almost 50 percent of patients with serious forms of cancer now survive for 5 more years and many are cured.

For patients under the age of 45 years, the national mortality from cancer has decreased.

Equally important are the recent discoveries in the fields of immunology, molecular biology, and carcinogenesis, which will undoubtedly have important clinical application during the next decade.

Despite the impressive gains, the budget of the National Cancer Institute has remained relatively fixed since 1977, but in current dollars has been declining as a consequence of inflationary pressures.

Many excellent programs in cancer centers that were built up with such great enthusiasm and expectation during the past decade are now very much in danger.

We note with considerable alarm that the newly proposed administration budget will result in a loss of funding of 16 of 20 cancer research centers up for renewal in fiscal year 1984.

If this policy is not reversed by Congress, then all cancer centers funded by the National Institutes of Health will soon be in jeopardy. This will result in the loss of one of the major achievements of the national cancer program, specifically the provision of a mechanism for close interaction between basic scientists and the clinical cancer specialists, which has allowed for the rapid transfer of new technologies to the bedside.

The restriction of funding for individual cancer research applications has already led to significant cutbacks in personnel and in capabilities throughout the country.

The end result of this trend is predictable, specifically the reduction of flow of new information necessary for the prevention and treatment of cancer, the termination of many promising research projects, the disuasion of bright young professionals from pursuing a research career and the destruction of research careers of highly talented scientists of established productivity.

Senator Proxmire, in consideration of the past achievements and the great benefits which can now be realized from the national cancer program, the American Society of Clinical Oncology urges that your committee recommend the appropriation of $1.3 billion for the National Cancer Institute for fiscal year 1984, including the appropriations for cancer centers, cancer control, and the organ site programs.

Thank you for permitting us to make this presentation.

PREPARED STATEMENT

Senator PROXMIRE. Thank you, Dr. Schein, very much for an excellent presentation.

[The statement follows:]

STATEMENT OF PHILIP S. SCHEIN

Mr. Chairman,

I am Dr. Philip S. Schein, Professor of Medicine and Pharmacology at Georgetown University, and Scientific Director of the Vincent T. Lombardi Cancer Research Center at Georgetown University. I appear before you representing the American Society of Clinical Oncology, of which I am the President-Elect. The American Society of Clinical Oncology wishes to urge that the National Cancer Institute be provided a budget for fiscal year 1984 that is not only adequate to offset the effects of inflation, but which will enable the continued orderly growth of the remarkable National Cancer Program which has been developed under the leadership of the National Cancer Institute in carrying out the National Cancer Act of 1971 and its extensions.

THE AMERICAN SOCIETY OF CLINICAL ONCOLOGY

The American Society of Clinical Oncology, ASCO, was founded in 1964, and has grown rapidly to become the largest and most ecumenical organization involved in clinical cancer care, research and education. Its membership consists of almost 4,000 cancer specialists throughout the nation representing all of the clinical medical specialties and basic scientific disciplines involved in the prevention, early detection, diagnosis, and treatment of patients with cancer and the conduct of research and education in those areas. Its members include the nation's leading specialists in medical and pediatric oncology, diagnostic and therapeutic radiology, surgical and gynecologic oncology, as well as laboratory specialists in pathology, biostatistics, pharmacology, immunology and other areas of basic science. Approximately one-half of the members are medical practitioners caring for cancer patients in their offices and in the nation's many excellent community hospitals. Collectively, the Society represents this nation's major resource in clinical cancer research as well as for the training and education of the cadre of cancer physician specialists and researchers of the future. In addition to its other activities, the Society also publishes the Journal of Clinical Oncology, which invites original articles covering all aspects of oncology including prevention, diagnosis, management and treatment.

The importance of cancer as both a national and international health problem is well appreciated. It is estimated that during the course of 1984 over 850,000 Americans will be diagnosed as having a new cancer and of these some 440,000 can be expected to die of their disease. In addition to the immeasurable human suffering associated with this phenomenon, it has been estimated that the cost to our country is many billions of dollars in lost wages and productivity, as well as hospital costs. It is in recognitio of the importance of this problem that Congress in 1971 legislated the National Cancer Act which provided the necessary resources for our scientific community to make the substantial commitment, which was required to begin to attack this important societal problem. Our concern, deeply shared by many others in the scientific community, is that the previous commitments of Congress and the Executive Branch of government have diminished, despite the tangible progress which has been made in our understanding of the causes and the fundamental biology of the process we call cancer, as well as the readily measured improvements in patient management.

THE NATIONAL CANCER PROGRAM

The National Cancer Institute, in carrying out the National Cancer Act, has established the most effective apparatus for cancer care and research ever developed. Its efforts extend to every major university, medical school and research institute in the United States in its search for the cure, prevention and management of human malignant disease. Clinical trials of newly developed treatment for cancer patients are now in progress in over 2,000 of the nation's hospitals. The National Cancer Program has influenced many basic scientists to direct their talents to problems in cancer biology and medicine, and they are now uncovering the causes and methods of preventing this disease. Many of the country's best and brightest young physicians have been recruited into training programs and careers in oncology. Over 60 new cancer centers have been developed, including 20 broadly based comprehensive centers. In turn the associated medical centers have responded with substantial commitments of their precious resources of personnel, space and developmental funds to the common goal. Through the interconnecting network of the cancer centers program, the cooperative cancer clinical investigative groups, and the cancer control program, the NCI has insured that new and successful treatments for cancer have rapid and widespread application as community standards of treatment. A strong and vigorous apparatus for the conduct of the National Cancer Program has been developed and is in place. The five or more years which were required to develop to train new physicians and basic scientists in cancer-related fields, to construct the laboratories, research beds and clinics, and to initiate clinical trials to validate new concepts of care, have been wisely invested. The most remarkable national medical research program yet known is now in place. And, most important, the National Cancer Program has already begun to realize its objectives. Almost 50% of patients with serious forms of cancer now survive for five or more years. For patients under the age of 45 years, the national mortality rate for cancer has definitely decreased.

EXAMPLES: REDUCED CANCER MORTALITY

Acute lymphocytic leukemia is the most common cancer among infants and children. This form of cancer was formerly 100% fatal. As the direct result of well designed clinical research to develop new treatments for leukemia, effective multidrug chemotherapy sometimes combined with radiation therapy, has led to a progressive improvement in survival. National cooperative cancer investigation groups supported by the NCI have demonstrated that over 60% of such children now enjoy continuous, complete remission and fully active lives for over seven years. It is widely believed that most of them are cured. Considering cancers of all types among children, over half can now be cured. Nonetheless, cancer remains the leading medical cause of death among children over the age of one year. Fortunately, over one-half of the nation's children with cancer are now being managed in clinical studies sponsored by the NCI. For patients with Hodgkin's disease, there has been an approximate 60% decline in mortality rate, paralleled by similar achievements in the more aggressive forms of non-Hodgkin's lymphomas. For testicular cancer, a tumor that involves young men during their most productive years of life, there has been a 43% decrease in mortality that can be directly attributed to the development of new forms of chemotherapy. It is currently estimated that 60% of men with such disease that has widely metastasized can be cured. The national mortality rate for ovarian cancer has decreased 38% as a result of improved staging and more effective application of surgery and chemotherapy. Breast cancer, the leading cause of cancer death in American women, has been the subject of intensive study of new methods for diagnosis and treatment. The use of radiation therapy after simple removal of the tumor, in place of mastectomy, has allowed many women to retain their breast without compromise in survival. The application of chemotherapy following surgery has resulted in a 15% decline in death due to breast cancer among younger women. Refinements in surgery, radiotherapy and chemotherapy for patients with bone cancer has resulted in a 19% decline in overall mortality. An 18% decrease in mortality among men with lung cancer is attributable to the successes of smoking cessation campaigns. The now widely applied PAP smear test for cervical cancer has permitted early detection prior to significant invasion of the cancer, and has led to a 47% decrease in national mortality due to this cancer.

Cancers of the gastrointestinal tract, as a group, represent the second leading cause of cancer mortality in the United States, with over 100,000 deaths directly attributable to these diseases. During the past 10 years, through the mechanism of carefully conducted control trials, we have demonstrated improved palliation and survival for patients with advanced stomach cancer, a 15-20% disease-free survival for patients with localized residual tumor following surgery, and the first evidence that combination chemotherapy can result in an increased survival in patients with stomach cancer who have had surgery with curative intent, but nevertheless remain at a high statistical probability for relapse. During this period more effective forms of chemotherapy have been developed, as well as technologic advances in radiation therapy and a greater sophistication in the use of nutritional support. With these measures, we anticipate that the survival rates for stomach cancer will demonstrate definite improvements during the next decade. Rectal cancer is well-recognized as a leading cause of cancer mortality in our country. Recent trials using postoperative radiation therapy and chemotherapy have demonstrated, for the first time, a significant reduction in relapse rate in patients who, following surgery, have a high probability for recurrence and death from this disease. Many of these studies are just reaching the point of maturation so that they can only now be brought into more general use by physicians throughout the country.

Importantly, the past decade has seen many discoveries in the fields of immunology, molecular biology and carcinogenesis, which will undoubtedly have important clinical application during the next decade. In particular, the concepts and methodologies relating to oncogenes, putative cancer-causing genes, may soon allow them to become the subject of chemotherapeutic attack. The development of monoclonal antibodies may have important applications in diagnosis and treatment. One of the major achievements of the National Cancer Program has been the provision of a mechanism for close interaction between basic scientists and clinical cancer specialists, and in particular the development of cancer centers throughout the nation. This close coordination of basic and clinical science has allowed for the rapid transfer of new technology to the bedside.

BUDGET FOR THE NATIONAL CANCER PROGRAM

Therefore, Mr. Chairman, it is evident to the members of the American Society of Clinical Oncology that we face an era of even greater opportunity in cancer research than in the first decade. We are at a uniquely advantageous point today because of the wisdom of the Congress in implementing the National Cancer Act of 1971 and its amendments. The improvements in survival and cure, which have been achieved through research, have taken at least five, and more often as many as ten years, to have an impact on national survival statistics; however, they are real and other substantial gains will soon follow if the National Cancer Program does not falter. The national resources of trained physicians and scientists, laboratories, research beds and clinics and the flexibility provided by the legislation, have led to the development of the necessary tools required for the application of important laboratory discoveries.

Despite these tangible gains, we have noted with great concern that the budget of the National Cancer Institute has remained relatively fixed since 1977, but in current dollars has been declining as a consequence of inflationary pressures. In 1981, for example, the inflation rate was 9.5% while cancer appropriations increased only 0.2%. The programs and cancer centers that have been built up with such enthusiasm and expectation during the past decade are now very much endangered, and some are threatened with being rapidly dismantled over the next two-to three-year period. We note with considerable alarm that the newly proposed Administration budget would result in the loss of funding for 16 of 20 cancer centers up for renewal in fiscal year 1984. This would affect all cancer centers in future years if this policy is accepted by the Congress. This comes at a time when we are in a position to begin to exploit the achievements of our past efforts. The restricted funding of individual research grant applications, which are approved and recommended highly for funding, has already led to significant cutbacks in cancer programs, in personnel and in capabilities throughout the country. We are losing, through attrition, some of our best cancer scientists and physicians; only one-quarter to one-third of approved grant applications are ever awarded any funds, and often in amounts reduced below the level recommended and required for the conduct of the program of investigation.

Mr. Chairman, the American Society of Clinical Oncology believes that this is a time of great opportunity in the short history of the National Cancer Program, and that we are in imminent danger of losing important gains. We urge, therefore, in consideration of the past achievements and great benefits which now can be realized from the national program, that your committee recommend the appropriation of $1,300,000,000 for the National Cancer Institute for fiscal year 1984, including the appropriations for cancer centers, cancer control program projects and organ site programs.

Thank you for permitting us to present our views. I would be pleased to answer any questions.

STATEMENT OF DR. TIMOTHY R. TALBOT, JR., CHAIRMAN OF THE BOARD, ASSOCIATON OF AMERICAN CANCER INSTITUTES

Senator Proximre. Our next witness is Dr. Timothy Talbot, chairman of the board of the Association of American Cancer Institutes.

Dr. Talbot. Mr. Chairman, I am Timothy Talbot. I am here on behalf of the Association of American Cancer Institutes, which is composed of about 60 cancer centers across the Nation—one of them in your own State, as you are fully aware. One of the best ones is in your own State.

I am also, for the last 25 years, in fact, at the Fox Chase Cancer Center in Philadelphia, which has developed into one of the major comprehensive centers recognized by the NCI.

I am going to depart from my written formal testimony, which has already been submitted because, as you're aware, during the last 2 weeks there was an event which was as much a surprise to you perhaps, as it was to us, when it took place. That is the proposed new administration budget for the defunding of NIH centers, including 20 of the 60 cancer centers now in existence for renewal in fiscal year 1984. There's also a center in the chairman's State, as you're fully aware—again, one of the best ones.

This new surprise is going to affect all 60 of these centers in succeeding years if that same process is allowed to continue. And it might do more than affect them. It might very well destroy a good many of them. The Congress, long before the Cancer Center Act was passed in 1971, supported core grants for cancer centers and ever since has given continuous support as the National Cancer Institute has so beautifully done.

The NCI Director himself has called the cancer center program the crown jewel of the Institute's efforts.

Last year, this committee gave it strong support in bill report language, which I would like to remind you of and for which we are grateful. Not only was there strong support for centers given, but also the NCI Director was instructed to report to this committee in time for the present hearings on the seeming trend downward of the funding levels for cancer center support grants.

In the written testimony that I have submitted—on the top of this sheet, you will see the way in which the ratio of cancer center support grants has dropped during recent years, and it's a matter for considerable alarm.

There was also a very strong statement by the House Energy and Commerce Committee in support of cancer centers and core grants. This was part of the authorization bill report for the biomedical research bill which failed to pass last year.

I should also like to point out that the committee felt so strongly they would like to protect the cancer centers from just this sort of attack that they provided a line item authorization in their bill and this year have inserted the line item again in their bill.

There was also a very strong statement by the Senate Labor and Human Resources Committee, chaired by your colleague Senator Hatch in his bill report language which accompanied the biomedical authorization bill which passed the Senate at the end of the session last year but failed in passage in the House.

It was unfortunate that the legislation did not also contain the line item authorization to protect cancer centers. But nevertheless, there is no question of the strong support from the entire committee for cancer centers.

The support by Congress and its key committees supporting NIH could not be more clear in support of cancer centers.

We sincerely hope, Mr. Chairman, that you will see that funds are restored for the cancer centers in the appropriations bill your committee will report out. And also, we would appreciate strong bill report language in support of these cancer centers.

We know that your chairman is also a member of the Senate Labor and Human Resources Committee and hope that he will find it possible to work there, as well, to support this.

Now, Mr. Chairman, I am going to refer only in a passing way to the many accomplishments that have taken place in the last decade. Others, perhaps by the dozens, have referred to these advances. I merely want to agree with those who have testified that we are poised for such continuation and for, I think, significant advances in this coming decade.

But more than anything else, I want to point out that these cancer center support grants are terribly important in ways that are very rarely understood. It is not just a matter of fact that it's money, which, of course, is important in every aspect of our lives. It's how that money is allocated and how it can be spent and for what purposes. It is the whole underpinning fabric upon which these centers have been built and upon which they must depend in the future.

And to suggest that you can take one kind of money away, as has been proposed by the administration, and substitute for it another kind that can't be used for that same purpose is, to say the least, a travesty of clear thinking.

And we want to make it very clear that this would be a disaster of no small proportion for these cancer centers. And I would hope that this important fact can be registered in the minds of all.

And I am grateful to you, sir, for being here. And I particularly don't want to leave without pointing out to you that the staff of this committee has always been consistently intelligent and helpful.

PREPARED STATEMENT

Senator PROXMIRE. Well, thank you, sir. I certainly agree with that latter observation, as well as your observation about our Wisconsin facility.

[The statement follows:]

STATEMENT OF T. R. TALBOT, JR.

Thank you, Mr. Chairman. It is a privilege for me to be here on behalf of the Association of American Cancer Institutes (AACI).

I am Dr. Timothy R. Talbot, Jr., Chairman of the Board of AACI, and former President of the Fox Chase Cancer Center in Philadelphia, where for 25 years I have been engaged in developing a major cancer center.

The Association of American Cancer Institutes had its origin in 1958 and now has about 63 institutional members, including all of the centers that are recognized by the National Cancer Institute as being Comprehensive Cancer Centers all of whom depend upon core grants. It is our common purpose to do all that we can to maintain a continuing momentum and forward thrust in our national effort in the attack on the problem of cancer.

Today, I want to focus briefly on three important points:

- The philosophy and purposes that have led to the development of cancer centers in the nation.
- The importance of maintaining a stable base of support for the cancer centers, especially in view of their prominent role in the fundamental and clinical aspects of biomedical science as these are related to cancer.
- Some research accomplishments and capabilities of the cancer centers.

Philosophy and Purposes

There were already several competent cancer centers in existence when the National Cancer Act was passed by the Congress in 1971. As I understand it, the National Cancer Institute already had, at that time, all of the authority it needed to support the programs of these and other centers. The only rational conclusion one can draw from the passage of the new law, and the authorities for cancer centers is, therefore, that the Congress wished to give special emphasis to the cancer problem; and as it did so, it also gave prominent emphasis to the value of cancer centers - both present and future. These centers were expected to become important reservoirs of competence in basic biomedical research related to cancer, and to develop equally important resources for conducting clinical investigation of high quality in a coordinated fashion.

A Stable Base of Support

Many cancer centers receive "core" grants from the NCI to pay for research resources which can be shared by investigators whose individual research grants would not otherwise cover the cost of their work. Cancer center core grants provide central support services and highly specialized laboratory services that are uniquely suited to the common interests of several investigators working in close proximity within a cancer center.

All of this was, fortunately, to be done within the framework of the peer review process.

To state the central points: core grants have made centers possible and have made them function. They have provided for "centerness;" for space in some cases; for shared equipment; have enhanced collegiality; have cemented staff together in a common purpose; have optimized interdisciplinary communication for both creativity and quick exploitation of new leads; and have been a major reason for the development of a network of centers where high quality creative work has emerged that has been funded in the competitive market of peer review processes. As we have often said, these grants are "the glue that holds the centers together."

Why are these core grants so important? It is not simply a matter of having more money. It is, instead, because of the ways in which that money is made available and how it can be used. The money that is supplied by core grants to centers is especially important because of the mechanism and form in which it comes to the centers.

If it is decided to reduce or obliterate core grants, and if as a result more R-01's and P-01's are thus made competitively available to the entire biomedical research community, then in some fashion that amount of money will need to be found to replace what was removed from the centers--it is also true that this "replacement" will, to the extent possible, be found from R-01 or P-01 grants. But total "replacement" of the core grants would be functionally impossible. Thus, the only places that would be victims of "taking from" would be the centers.

Modern biomedical research requires an institutional and organizational support system that is far different from the casual processes of the past. Core grants provide this essential infrastructure, cohesiveness and purpose without which our quality would be certain to suffer. A collection of individual R-01 and P-01 grants simply cannot, alone, establish or maintain a center that is designed for stability and vibrancy.

Thus, the major emphasis and thrust of centers is clearly aimed at gaining important new understandings - in other words, doing high quality scientific research, in both the laboratory and clinical arenas, that will continue to lead us to a rational meaningful attack on the problem of cancer.

Included with this statement are two pages which show in graphical form how the stability of core grants has been eroded during the last several years. (The data upon which these graphs are based were obtained with the help of the Cancer Centers Branch, Division of Resources, Centers and Community Activities of the NCI.) These data reveal that the relationship of core grant dollars to total NCI or NIH dollars awarded to cancer centers has shown a consistent trend of reduction. We regard this as a dangerous threatening factor and believe that it is urgent to take corrective measures.

Research Advances in Centers

I shall not try to burden the committee with excessive amounts of information, but would like to give some examples of the kinds of advances brought about by research in these centers.

At the Fox Chase Cancer Center the work of Dr. Baruch S. Blumberg on Hepatitis B virus - work for which he won the Nobel Prize in 1976 - and primary cancer of the liver, demonstrates how a cancer center program facilitates the transition of basic research to clinical care. There is a group of people who are at high risk of developing primary liver cancer because of a high rate of persistent infection with Hepatitis B virus. This is one of the first instances where a major cancer may be controlled by prevention and/or early detection and treatment with a vaccine developed against the hepatitis B virus; and as noted, the work has been done in a cancer center utilizing the findings of basic science and transferring them quickly through clinical research to applied clinical activities.

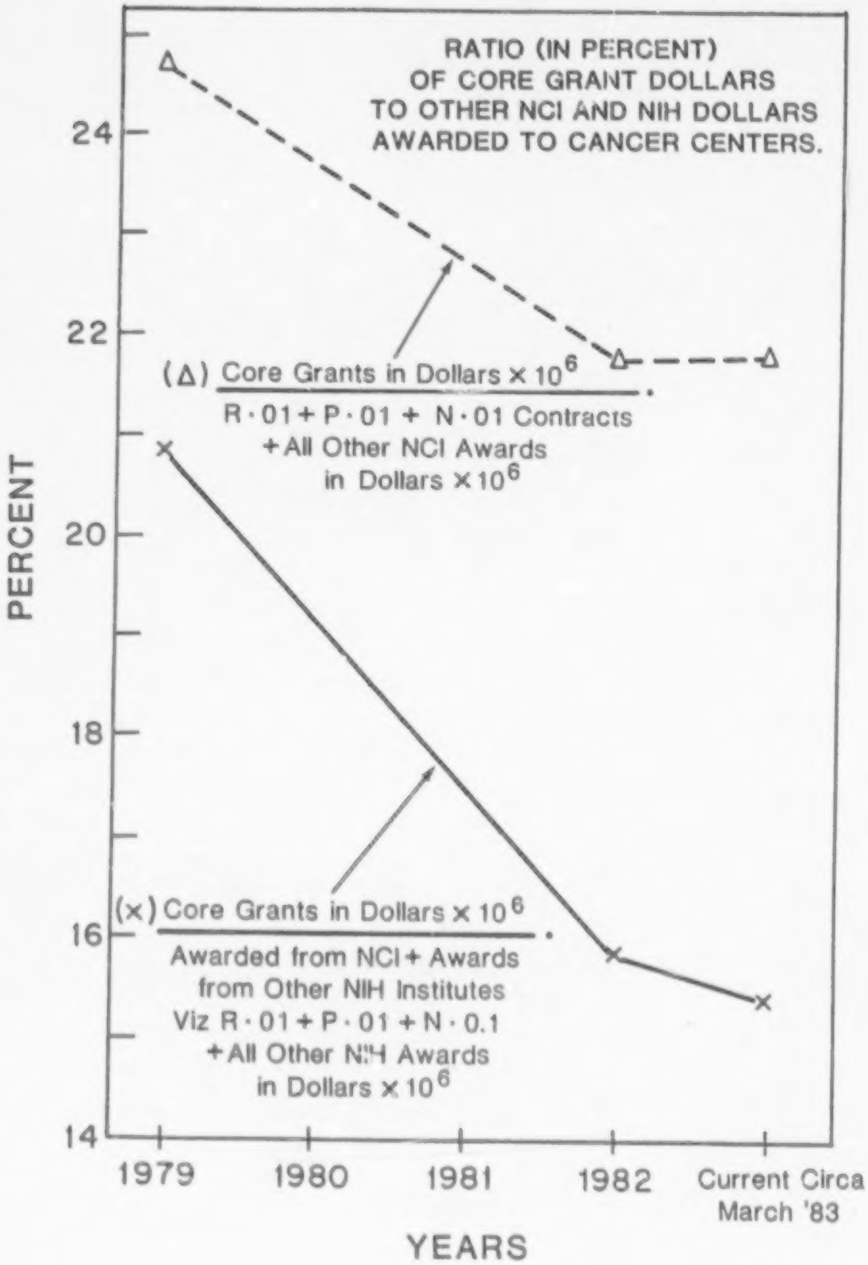
We are witnessing, as this committee has heard from many respected sources, an explosion of important, exciting and apparently increasingly relevant new scientific information. These advances are being provided by the entire biomedical research community; but it is our belief that the potentialities for further advances in the immediate and long-range time frames will be greatest for the cancer field in the laboratories and clinics of the cancer centers.

What we are now seeing is undoubtedly due to the stability of support for biomedical research and for centers, that the Congress, including this committee, has provided during the last three or four decades. The single most important aspect of support for these endeavors is, clearly, a rational stability. The rewards of past support and effort are now coming out - we must see to it that our efforts in this decade will be continued so that we will always have our on-going developing reservoir to help us deal with the future. For these reasons we, among many of our colleagues, continue to plead the case for stable funding of the cancer centers, and the biomedical research system of this nation, of which these centers are such an important part.

Mr. Chairman, a subcommittee of the House of Representatives has recently agreed to specific dollar figures for specific purposes regarding the support of the NCI. These are: $1.16 billion for the NCI, plus $64,000,000 for section 413 within the NCI, and $93,000,000 for cancer center support grants (core grants) in section 415 within the NCI. These are figures for the 1984 fiscal year. We wish to endorse these proposals and we want to enlist your support for them and for these specific designations.

Mr. Chairman, we wish to express our thanks for the recognition of cancer centers that was given by this committee in the past. We wish to place ourselves at your disposal if we can be of help in any way, including the providing of information or evaluation whenever it can be useful.

Thank you for your attention and interest.


RATIO (IN PERCENT)
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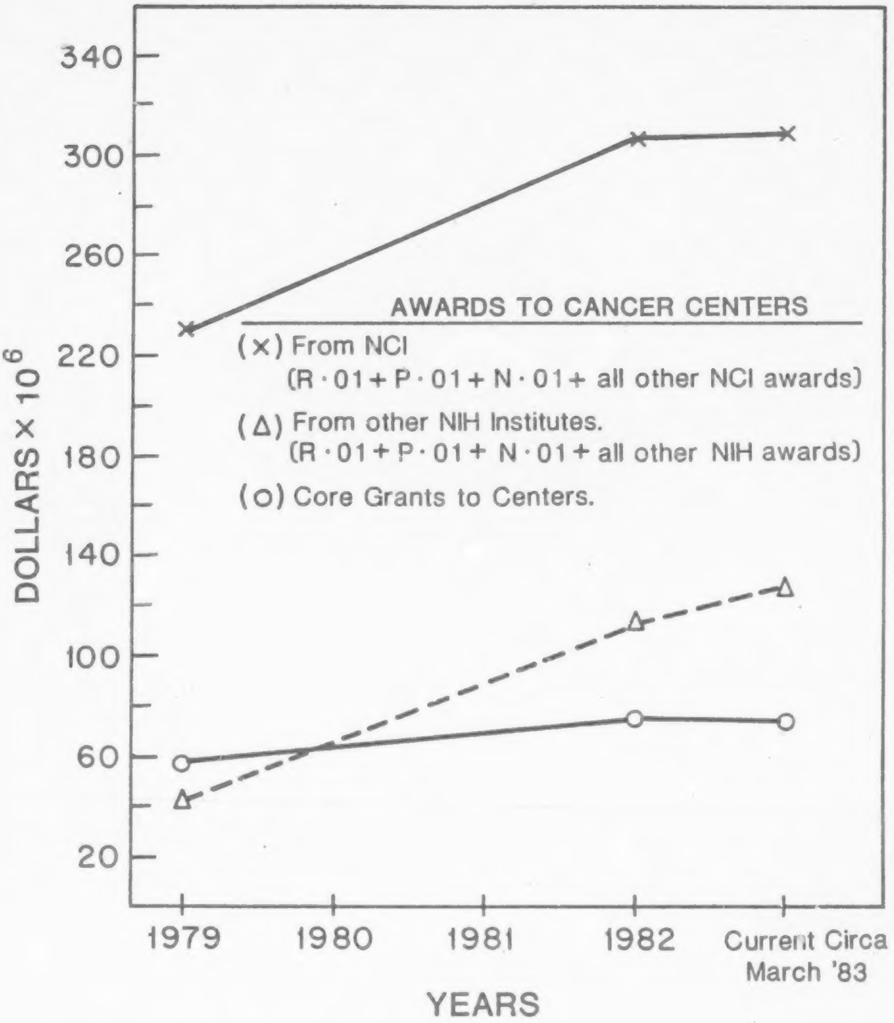
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STATEMENT OF JAMES A. SWOMLEY, MANAGING DIRECTOR, AMERICAN LUNG ASSOCIATION

Senator PROXMIRE. Now we'll have witnesses on the National Heart, Lung, and Blood Institute. Our first witness will be James Swomley, manager director, American Lung Association.

Mr. SWOMLEY. I would like to introduce Dr. Edward Sewell, who is president-elect of the American Lung Association. He is a pediatrician from Philadelphia and he is in town today.

Senator PROXMIRE. Welcome, Dr. Sewell.

Dr. SEWELL. Thank you, Senator.

Mr. SWOMLEY. I am the managing director of the American Lung Association, which is American's oldest nationwide voluntary health agency. We were organized back in 1904 to fight tuberculosis and over the years we have increased our concerns to the prevention and control of all lung diseases.

We're particularly pleased to have this opportunity to talk to you this morning regarding our concerns as far as the Federal Government and its goal in the prevention and control of lung disease is concerned.

We have filed our statement for the record, and I would just like to briefly summarize some of the points in that statement and in a supplemental one-page statement that we have also added to the record.

The problem of lung disease has grown considerably in this country in recent years. Some of this relates to the cigarette and the long-time effects of smoking. Some of it relates to occupational health hazards, environmental problems, and our aging population.

Taken collectively, lung disease represents the third leading cause of death in this country. And I am talking about a variety of problems, such as infectious problems, pneumonia, tuberculosis, chronic obstructive lung disease, such as emphysema, chronic bronchitis, and a number of other diseases which all affect our lung health.

The Federal Government has played an extremely important role through the years in battling these diseases. Its greatest contributions have been in terms of its premier role in medical research and in terms of the leadership which it is given in certain key areas of prevention. And I would like to, in particular, emphasize the role of the National Heart, Lung, and Blood Institute and its Division of Lung Disease in this battle. The research role played by this Institute has been crucial in some of the great accomplishments in this country. And when we consider the fact that lung disease is responsible for a $45 billion health bill to America and has profund impact on everything from medicare and medicaid to health insurance costs and hospital occupancy, all of these things, we recognise the importance of this problem and how key the research developments have been and how key prevention is in holding down these costs and reducing the death and morbidity from lung disease.

We are concerned that we have not maintained our momentum in terms of research. In other words, there has been a real loss in terms of the real dollars going into research, the number of scientists that are being supported in the projects. So that even though there may have been some growth in the actual dollars, we are concerned with maintaining the momentum.

A couple of other concerns come to mind, such as the tuberculosis problem in this country. We've come a long way from the days when tuberculosis was the leading cause of death, but it still continues to be quite significant in some of our key population areas. Part of this relates to migration from abroad and other problems of this nature. And we'd like to stress the importance of TB project grants. It had been our hope that the prevention block grants would take care of this problem, but we find that not a single State, to our knowledge, has put any of its block grant money into this problem.

And I would also like to stress the importance of the Federal Government's role in smoking education. The dollars are miniscule. The support, as I understand it, in the past year or so has been at the $1,900,000 level. We are suggesting an increase in this area. I understand the President has suggested an increase as well, and we feel that the Federal role is very, very key in terms of the statistical studies, the surveys in having the Federal Government indicate its concern for this, the most serious of all preventable health problems in America. Three hundred forty thousand Americans die prematurely each year from cigarette smoking.

That is briefly a summary of some of the points in the testimony. And I would like to express my appreciation to you, sir, to your committee and to Congress for the importance that they have given to health and to the programs which I have described.

Senator PROXMIRE. Thank you very much, Mr. Swomley and Dr. Sewell. We are happy to have you here. I am especially happy to hear your recommendation for smoking education. I couldn't agree with you more.

Mr. SWOMLEY. Thank you.

Senator PROXMIRE. Thank you, sir.

Unfortunately, you weren't here when I stated the rules. We have a 5-minute rule, and I apologize. It's unfortunate with the very distinguished witnesses we have before us to cut them off at 5 minutes. Normally, we'd like to have a half hour or hour to really go into this in detail, but we just can't do it today with the number of witnesses we have.

Mr. SWOMLEY. I understand.

PREPARED STATEMENT

Senator PROXMIRE. I want to thank you very much for appearing here and your fine statement. It will undoubtedly have an effect on the committee and on our actions.

So thank you, sir.

Mr. SWOMLEY. Thank you.

[The statement follows:]

STATEMENT OF JAMES A. SWOMLEY

Mr. Chairman and Members of the Subcommittee:

Thank you very much for the opportunity to put before you the views of the volunteers of the American Lung Association and and the scientists and health professionals of the American Thoracic Society, ALA's Medical Section. I am James A. Swomley, Managing Director of the American Lung Association.

Our organization is the country's oldest voluntary health Association. We began by working to control and prevent tuberculosis, and that effort continues, but our current mission now takes in the broad spectrum of all lung diseases. These diseases constitute a devastating public health problem in the United Sates. They rank third among the leading causes of death. Respiratory diseases are an even greater cause of morbidity and disabilty. They account for more than 20 percent of all physician contacts, 12 percent of short-term hospitalization and more lost work days than any other category of illness.

The direct and indirect costs of lung diseases are about $45 billion annually and with the aging of our population, these cost trends are definitely upward. Clearly, lung disease must be dealt with as a priority need. We urge that public policies call for increased efforts by federal programs that can make a significant difference in our lung health future.

The federal government programs give strength and leadership to our entire health care system. The ALA/ATS has evaluated the proposed FY 1984 budgets for the National Heart, Lung and Blood Institute and its Division of Lung Disease, as well as other Institutes and agencies responsible for lung research, training, prevention and education. We are deeply concerned that the low budgets proposed in most instances will cost more in the long run than any supposed short-term savings. Our concern is for missed research opportunities and dismantled programs which will cause lost momentum in key areas. In the absence of adequate federal support, neither state nor local governments, nor the private sector are financially capable of continuing these programs.

We urge restoration of adequate budgets to these programs and returning them to a level of national priority. Congress, in adopting its Continuing Resolution for FY 1983 in December, gave its strong backing to the restoration of the nation's health as a priority and we commend your leadership.

National Heart, Lung and Blood Institute

ALA/ATS recommends an appropriation for FY 1984 of at least $685 million for NHLBI. The President's budget calls for a .8 percent "increase", which when inflation is taken into account, would actually result in a substantial decrease. Yet, the NHLBI programs deal with major health problems facing our citizens today--heart disease and chronic obstructive pulmonary disease, a category that includes emphysema and bronchitis. This Institute has been consistently underfunded for the past six years. Its budget, in terms of constant dollars, declined by 10 percent between 1978 and 1983.

Despite these fiscal handicaps, the record of scientific achievements at NHLBI over the past decade has been outstanding. In the lung area alone, deaths from neonatal respiratory distress syndrome, a leading cause of death and morbidity among new borns, have fallen steadily as a result of such federally sponsored research. Basic research on the structure and function of the lung and on the development of diseases of the air ways and lung parenchyma continues to disclose the ways in which dust particles and toxic vapors associated with job, home and air pollution cause chemical injury to the lung. This understanding offers new opportunities for treatment and prevention of pulmonary diseases and control of the costly and debilitating effects of chronic bronchitis, asthma, emphysema, pulmonary fibrosis and pulmonary vascular diseases.

The knowledge is at hand to mount a sorely-needed attack on chronic obstructive lung diseases (COPD), now the fifth cause of death in the U.S. Such an offensive would make it possible to reverse COPD trends in the next decade. Similar strategies could be applied to cystic fibrosis, the most common chronic fatal respiratory disease of children. Such major new initiatives will only be possible with substantial increases in the NHLBI budget that will allow for real growth on a consistent basis.

National Institute for Allergy and Infectious Diseases

ALA/ATS recommends an appropriation for FY 1984 of $300 million for NIAID. The research responsibilities of NIAID include a number of respiratory disorders, such as tuberculosis, asthma, the influenzas and pneumonias and a host of other bacterial, viral and immunologic diseases that affect the lung. It was NIAID whose support led to an effective vaccine against pneumococcal pneumonia.

NIAID supported studies have identified opportunities for increased research in human biology. These studies covered bronchial asthma, problems of allergic children, drug allergy, occupational asthma, and related immune disorders.

National Institute of Environmental Health Sciences

ALA/ATS recommends an appropriation for FY 1984 of $170 million for the NIEHS. A significant portion of the work of this Institute relates to pulmonary health. Among its important and timely work is research in the pathology of lung disease related to the effects of the processing of coal. Other important studies are being conducted in environmental carcinogenesis and the lung. NIEHS has been given the lead role in the National Toxicology Program and is working closely with the National Institute for Occupational Safety and Health to set up a practical system to identify and evaluate multitudinous chemical hazards.

National Institute for Occupational Safety and Health

ALA/ATS recommends an appropriation for FY 1984 of $69 million for NIOSH. This Institute has a primary role in national efforts to protect the work force from hazards through the development of workplace standards for exposure to hazardous substances. Much of the Institute's work at the Appalachian

Laboratory is devoted to respiratory disease and how it develops as result of occupational exposure. A vital part of the NIOSH program is its Educational Resource Centers program which is responsible for a key portion of manpower development in the prevention control of occupational lung disease and other related diseases in the workplace. This program has once again been deleted from the Administration's proposal. It is recommended that funding in the amount of $8 million for the ERC program be included.

Pediatric Pulmonary Centers

ALA/ATS recommends an appropriation for FY 1984 of $4 million for Pediatric Pulmonary Centers which receive funding through the Maternal and Child Health Block Grant.

The PPCs function as referral centers for the expert diagnosis and treatment of pediatric pulmonary problems. Many of the children admitted have asthma or cystic fibrosis--some are infants with life-threatening respiratory problems. The centers also provide training opportunities in pulmonary disease for medical and paramedical personnel.

Tuberculosis Project Grants

ALA/ATS recommends an appropriation for FY 1984 of $11 million for Tuberculosis Project Grants administered through the Centers for Disease Control. Congress approved this program in recognition that a special step had to be taken in order to assure getting limited federal funds to problem areas.

Funding for TB control programs has suffered severely in the previous decade under the block grant concept and with the added problem of refugees, the steady decline in TB has stopped.

Preventive Health and Health Services Block Grant

ALA/ATS recommends an appropriation for FY 1984 of $96 million for the Preventive Health and Health Services Block Grant which is administered by the Office of the Assistant Secretary for Health. This grant program includes home health incentive, health education/risk reduction, emergency medical services, and provides a basic source of funding for chronic disease control programs.

Office of Smoking and Health

ALA/ATS concurs with the President's FY 1984 recommendation of $3.5 million for the Office of Smoking and Health, which is in the Office of the Assistant Secretary for Health in the Department of Health and Human Services.

Cigarette smoking is estimated to cause approximately 340,000 premature deaths each year in the United States. It also takes a heavy toll in terms of illness and disability, and is a significant factor in Medicaid, disability and welfare costs. The modest budget of this program has paid for itself many times over and has been a valuable resource to organizations such as ours.

Office of Health Promotion

ALA/ATS concurs with the President's FY 1984 budget recommendation of $3 million for the Office of Health Promotion, which is in the Office of the Assistant Secretary for Health.

The program provides a focal point for the federal initiatives related to prevention of illness and promotion of a healthy lifestyle.

* * *

Discretionary federal health programs are exceptionally cost-effective, ultimately reducing the need for further outlays for medical care. Further cuts in the programs cited above, or even compromises that result in non-growth, would be counter-productive, to say the least. We urge you to sustain the health momentum reflected in the Continuing Resolution adopted for this year.

Thank you.

SUMMARY OF AMERICAN LUNG ASSOCIATION TESTIMONY ON FY 1984 HEALTH APPROPRIATIONS

The American Lung Association and the American Thoracic Society, ALA's Medical Section, recommend the following fiscal 1984 appropriations:

1.	NATIONAL HEART, LUNG AND BLOOD INSTITUTE:	$685 million
2.	NATIONAL INSTITUTE FOR ALLERGY AND INFECTIOUS DISEASES:	$300 million
3.	NATIONAL INSTITUTE OF ENVIRONMENTAL SCIENCES:	$170 million
4.	NATIONAL INSTITUTE FOR OCCUPATIONAL SAFETY AND HEALTH:	$ 69 million
5.	PEDIATRIC PULMONARY CENTERS (INCLUDED AS PART OF 15 PERCENT SET ASIDE OF MATERNAL AND CHILD HEALTH BLOCK GRANT):	$ 4 million
6.	TUBERCULOSIS PROJECT GRANTS--CENTERS FOR DISEASE CONTROL:	$ 11 million
7.	PREVENTIVE HEALTH AND HEALTH SERVICES BLOCK GRANT--CDC:	$ 96 million
8.	OFFICE OF SMOKING AND HEALTH--ASSISTANT SECRETARY FOR HEALTH:	$ 3.5 million
9.	OFFICE OF HEALTH PROMOTION--ASSISTANT SECRETARY FOR HEALTH:	$ 3 million

SUPPLEMENTAL STATEMENT

April 27, 1983

Since my original testimony was prepared, the administrative budget proposals for FY84 for the National Institutes of Health have been modified somewhat. The bottom line request of $4.077 billion has remained unchanged and is far short of the realistic funding needed to maintain the program growth and our national leadership in research.

An additional $9.7 million has been allocated by the Administration to the National Heart, Lung and Blood Institute for a revised total of $637.7 million. While this is a move in the right direction, the NHLBI would still only be "increased" 2.4 percent over what Congress has provided for the current fiscal year. Considering the decline this Institute has suffered in terms of constant dollars over the past six years, this modified recommendation continues to be unrealistic. Keep in mind that the mandate of NHLBI includes four of the ten leading causes of death in this country. It is our recommendation that the FY84 appropriation for NHLBI be at least $685 million.

I would like to give additional emphasis to the tuberculosis funding needs cited in my original testimony. A program of Tuberculosis Project Grants was authorized by Congress in 1981 in order to assure getting limited funds to problem areas. This was intended to supplement the opportunity of states to provide basic tuberculosis control programs from the Preventive Health Services Block Grant. However, a survey of how states are using their block grant money has not as yet identified a single state that is using Block Grant funds for tuberculosis. Therefore, the Tuberculosis Project Grant source of funding becomes even more imperative. It is our recommendation that the FY84 appropriation for Tuberculosis Project Grants be for the full $11 million as authorized.

STATEMENT OF DR. PAUL A. EBERT, PRESIDENT, AMERICAN COLLEGE OF CARDIOLOGY

Senator PROXMIRE. Dr. Paul Ebert, president of the American College of Cardiology.

Go right ahead, sir.

Dr. EBERT. Mr. Chairman, I am Paul A. Ebert, chairman of the Department of Surgery at the University of California, San Francisco School of Medicine.

I appear before you today representing the 12,000-member American College of Cardiology of which I am currently president.

My remarks will focus on issues relevant to the National Heart, Lung, and Blood Institute and the National Library of Medicine.

The broad responsibility of the National Heart, Lung, and Blood Institute is clearly evident by the fact that 4 of the 10 leading causes of death and medical problems fall under the jurisdiction of this institute:

No. 1 is the disease of the heart.

No. 3 is cerebrovascular disease.

No. 5 is chronic obstructive lung disease.

And No. 9 is arteriosclerosis.

In light of this broad responsibility, we feel it is important to consider the NHLBI funding for the last 6 years, as compared with other institutes.

Our comparative charts have shown that between the fiscal year 1977 budget and the administration's proposed budget for fiscal year 1984 there is a 57-percent increase for NHLBI versus 72 percent for all institutes smaller in mandate.

The American College of Cardiology wishes to recognize the work of this subcommittee and compliment it for its increase last year of 11 percent, which has permitted, for the first time in many years, real growth in heart and vascular research.

Our concern for adequate funding is placed in further perspective by the fact that diseases of the heart and blood vessels affect at least 40 million Americans and rank first in the cause of death, limitation of activity, short-stay hospital discharges, hospital days, and disabled-worker benefits.

Plus, the total economic burden of cardiovascular diseases is estimated to be more than $75 billion annually, which is over one-fifth of the total cost of all health illnesses.

The positive side is that in 1981, for the first time since 1949, cardiovascular diseases accounted for less than 50 percent of all U.S. deaths. We think the reasons for this trend reside in the Federal commitment to research and training in heart, lung, and blood diseases.

The programs most affected by inadequate funding within the NHLBI are areas of major importance. We clearly need strong national research and demonstration centers. Fundamental research, in its basic application to disease States, needs to be increased. A community surveillance system for cardiovascular and other chronic diseases would enhance the understanding of many factors that influence trends in the development of heart and lung disease.

The efficacy of various therapeutics in the treatment of heart failure needs evaluation.

In addition to research needs, an ample number of well-trained and dedicated clinicians and scientists must be available to continue our strong research programs.

The American College of Cardiology agrees with the House Appropriations Committee's report of last year that the future vigor of biomedical research obviously depends on the continued availability of new entrants into the field, with new ideas, new approaches, and new enthusiasms.

It is also clear, by your companion report and funding recommendations, that your committee in the past fully appreciates the attraction of alternate careers and the detrimental effects of an unstable Federal commitment to research.

The American College of Cardiology strongly hopes that the NIH will augment NRSA stipends with a physician allowance to match the equivalent House staff or residency compensation of training institutions.

We would, therefore, recommend that the funding for the total NRSA component of NIH approach $200 million in fiscal year 1984.

We strongly recommend that considering the multiple challenges facing the NHLBI, that the fiscal year 1984 funding level for NHLBI be no less than $698 million, including the research, prevention, education, and control and training activities of the Institute.

We do not believe that the President's request of only $637 million, $15 million over the fiscal year 1983 continuing resolution level, is adequate to maintain the research momentum necessary within this Institute.

The American College of Cardiology also believes that advances in medicine are heavily dependent on the effective and efficient dissemination of biomedical information to the Nation's health professionals. Thus, the need of the National Library of Medicine is of extreme importance to a strong continued research program.

Last year more than 2 million searches were performed by using NLM data bases. Our medical library assistance programs provide grant support for establishment, development, and enhancement of health information services for all of our Nation's professionals.

A regional medical library network has been created that coordinates information delivery services across this country. The importance of these library assistance programs is paramount to our continuing education and research base.

Thus, we continue to recommend a level of $10,500,000 in fiscal year 1984 to enhance these important library programs.

In summary, the National Library of Medicine plays a key role in delivering effective and efficient health information to the biomedical community.

We urge the committee to fully support the programs of the National Library of Medicine and increase the budgetary levels of the extramural programs to their former levels. In order to achieve this, we recommend that the fiscal year 1984 President's budget be increased by $1,500,000 to a level of approximately $51 million.

The American College of Cardiology appreciates having had the opportunity to present these views, and we thank you very much for your time.

Senator PROXMIRE. Thank you, Dr. Ebert, very much.

[The statement follows:]

STATEMENT OF DR. PAUL A. EBERT

Mr. Chairman and Members of the Subcommittee

INTRODUCTION

I am Dr. Paul A. Ebert, Chairman of Surgery at the University of California San Francisco School of Medicine. I appear before you today representing the 12,000 member American College of Cardiology[1] of which I am currently President. My remarks will focus on issues relative to the National Heart, Lung, and Blood Institute and the National Library of Medicine.

I would like to place our concerns in perspective with some considerations on the responsibilities of the NHLBI and the potential impact of its activities. As you know, the National Heart, Lung, and Blood Institute's responsibility is both unique and broad. In 1972 and 1976, Congress recognized the overlapping of many of the biological and, consequently, research problems common to diseases of the heart, lung, and blood and restructured the make-up of the National Heart Institute by creating first the National Heart and Lung Institute and then the National Heart, Lung, and Blood Institute. Four of the ten leading causes of death and medical problems fall under the jurisdiction of the NHLBI (diseases of the heart (#1), cerebrovascular diseases (#3), chronic obstructive lung disease (#5), and arteriosclerosis (#9)).

In light of this broad responsibility, it is pertinent to consider NHLBI funding for the past six years as compared with other institutes. The attached charts (Appendix) compare the percentage and dollar funding changes of individual institute budgets, as well as the increase for the other institutes with similar figures for NHLBI. This comparison shows that the differences between the FY 1977 budget and the Administration's proposed budget for FY 1984 are +57% for NHLBI versus +72% for all institutes smaller in mandate and size than NHLBI. The

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[1] The American College of Cardiology (ACC) is a nonprofit professional medical society, dedicated to ensuring optimal care for persons with cardiovascular disease or those with the potential for developing cardiovascular disease and, through education and socioeconomic activities, the prevention of cardiovascular disease.

College appreciates the Subcommittee's support last year of the 11% increase for NHLBI, and the acknowledgement of the significant contributions well-funded research and training programs can make. That increase for the first time in years, will permit real growth in heart and vascular research. It is essential that this year's budget also allow the NHLBI to continue to capitalize on significant research opportunities.

Our concern for adequate funding is placed in further perspective by the following considerations: (1) Diseases of the heart and blood vessels affect at least 40 million Americans and rank first in cause of death, limitation of activity, short stay hospital discharges and hospital days, and disabled worker benefits. (2) The total economic burden of cardiovascular disorders is estimated to be more than $75 million annually (over one-fifth of the total cost of illness).

Such statistics fortunately are balanced by the fact that in 1982, for the first time since 1949, cardiovascular disease accounted for less than 50 percent of all U.S. deaths. In the age group 35 to 45 there has been a 36 percent decline in deaths over the last ten years. We believe that the reasons for these trends reside in a continuing Federal commitment to research and training.

At this point, we would like to mention a number of meritorious and promising program opportunities within NHLBI that cannot be funded within the Administration's NHLBI FY 1984 budget request. We believe that NHLBI's inability to fund these opportunities is especially unfortunate given the Institute's demonstrated potential for continued national progress in the prevention, diagnosis, and treatment of diseases of the heart, lungs, and blood.

National Research and Demonstration Centers

The NHLBI seeks to expand its successful Specialized Centers of Research program by establishing certain new specialized centers that include demonstration and/or evaluation components. This will ensure that research results will be appropriately disseminated and applied.

Fundamental Research and Its Application to Disease States

New information about the relationship between arteriosclerosis and the behavior and proliferation of endothelial cells of the arterial walls shows great potential for advancing the understanding, treatment, and prevention of arteriosclerosis. This research direction should be fostered.

A Community Surveillance System for Cardiovascular and Other Chronic Diseases

It has been proposed that several communities be monitored for morbidity and mortality data relating to the incidence of first and recurrent myocardial infarctions and cardiac deaths, total mortality and mortality from major diseases, changes in coronary heart disease (CHD) risk factor levels, and changes in the medical treatment of CHD. Such information could enhance understanding of factors that influence trends in the development of heart disease, regional differences in coronary heart disease rates, differences in the effects of prevention versus treatment of disease, and the relative impact of personal and social factors.

Efficacy of Therapeutics in Congestive Heart Failure

Presently, a wide variety of therapeutic approaches exist for congestive heart failure. While all of the agents employed have been shown to be of some benefit in the management of patients with chronic heart failure, there is currently inadequate information regarding the long-term effects on the circulatory system for such agents and practically no information is available on their effects on survival.

In addition to the above areas increased knowledge of and developments in the following could offer significant eventual practical application if funded:

- Improved methods for the diagnosis of peripheral vascular disease;
- Further investigations into the basic etiology and pathophysiology of valvular heart disease;
- Improvements in understanding of the pathogenesis of congenital cardiac malformations;
- Development of enhanced minimally invasive and non-invasive methods for the detection of atherosclerosis;
- Continuation of studies in improved pharmacological and non-

pharmacological methods for long-term management of hypertension and assessment of the benefits and risks of such regimens;

- Continuation of epidemiological studies of risk factors for cerebrovascular disease;
- Indications for and efficacy of the injection of the enzyme, streptokinase, directly into affected arteries of the heart to relieve coronary obstruction;
- Assessment of percutaneous transluminal coronary angioplasty (PTCA) as a possible alternative, in certain instances, to coronary artery bypass surgery.

In addition to the above comments dealing in large part with extramural research opportunities, the importance of a strong and adequately funded intramural research program needs to be stressed. The successes of the intramural program over the past years demonstrate that it is a vital component of the NIH research enterprise.

We trust that these few areas of investigation demonstrate that we are pleased with the strong commitment of your Subcommittee to heart and vascular research. However, for us to discharge our responsibilities as physicians and researchers, this strong commitment must continue.

In addition to research needs, an ample number of well-trained and dedicated clinicians and scientists must be available for our research programs to succeed. The College shares the concern expressed last year by the House Appropriations Committee that "the future vigor of biomedical research obviously depends on the continued availability of new entrants into the field with new ideas, new approaches and new enthusiasms." Further, it is clear that this Committee also fully appreciates the attraction of alternative careers and the detrimental effect on an unstable Federal commitment to research.

The NIH data details the dramatic decline of physicians entering careers in academic investigative medicine, particularly in heart and vascular fields and documents the decline in the percentage of postdoctoral fellows holding clinical degrees, from 47 percent in 1975 to 36 percent in 1980. This occurred, however, as NIH notes, during the time when the absolute number of clinical postdoctorate fellows has remained relatively constant at an average of 1,900 per year. The report highlighted a number of factors which may discourage young physicians from entering research careers, including the fact that research training positions under the NRSA Program return to the trainee some $6,000 per year less on the average than clinical training positions. NIH noted that it has considered augmenting NRSA stipends with a "physicians' allowance" to match the equivalent housestaff compensation at training institutions. The College would recommend that this salary differential be adopted by the NIH. Such an approach would require additional funding of $3.5 million in FY 1984 to maintain the same number of total trainees. We, therefore, recommend that funding for the total NRSA component of NIH approach $200 million in FY 1984.

In total, considering the immense challenges facing the NHLBI in the research and training areas, the College recommends that the FY 1984 funding level for NHLBI be no less than $698 million, including the research, prevention, education and control and training activities of the NHLBI. We do not believe that the President's request of $628 million, only 0.9 percent over the FY 1983 Continuing Resolution level signed into law by the President, is adequate to maintain the research momentum and productivity of NHLBI.

National Library of Medicine

The American College of Cardiology believes that advances in medicine are heavily dependent upon the effective and efficient dissemination of biomedical information to the Nation's health professionals. The biomedical community relies heavily upon NLM's online bibliographic retrieval network to provide health professionals with rapid access to the world's most important medical literature. This network currently encompasses some 2000 online centers located at universities, medical schools, hospitals and government agencies. Last year more than 2 million searches were performed using the NLM databases.

The Medical Library Assistance Programs provide grant support for the establishment, development, and enhancement of health information services for the Nation's health professionals. A Regional Medical Library Network has been created that coordinates information delivery services across the country. Through this network of more than 3000 libraries, approximately 15 million interlibrary loan requests have been filled since the network's inception.

Research grants are made to assist hospitals in the development of their library and information services. Other grant programs support research into the application of computers to biomedical information sciences, the training of qualified investigators in this discipline, and the publishing of selected materials important to biomedicine. These grant programs have experienced serious retrenchment in recent years. They should be restored to their previous level of support and expanded considerably in the future. Therefore, we recommend a level of $10.5 million in FY 1984 to enhance these important library assistance programs.

With the recent merger of the National Medical Audiovisual Center into the activities of the Lister Hill National Center for Biomedical Communications, the enlarged and integrated resources of the Lister Hill Center provide an even greater opportunity to apply computer and communications technology to problems in the fields of information storage and retrieval, health professional education, and health care delivery.

In summary, the NLM plays a key role in delivering effective and efficient health information to the biomedical community. We urge the Committee to fully support the programs of NLM and increase the budgetary levels of the extramural program to its former levels. In order to achieve this, we recommend that the FY 1984 President's budget be increased by $1.5 million to a level of approximately $51 million.

The College appreciates having been given the opportunity to present its views. We would be pleased to provide you with any additional information you might wish and, of course, answer any questions you may have.

AMERICAN COLLEGE OF CARDIOLOGY

Comparison of Institute Budgets:

1977-1984 PRESIDENT'S BUDGET

Institute	Percent Change 1978 Level from 1977	1979 Level from 1978	1980 Level from 1979	1981 Level from 1980	1982 Level from 1981	1983 Lev. from 1982	1984 Pres.Bu from 1977
NCI	+7.0%	+7.4%	+6.8%	−5.3%*	−0.4%	+ 4.3%	20.6%
NHLBI	+12.9	+13.1	+4.2	+4.2	+1.9	+11.3	57.4
NIADDK	+18.5	+16.3	+12.7	+8.3	−0.2	+12.0	81.8
NINCDS	+14.7	+19.1	+13.9	+4.4	+5.5	+11.2	88.1
NIAID	+15.1	+17.9	+12.6	+7.8	+1.9	+16.0	97.0
NIGMS	+12.6	+20.3	+12.6	+5.4	+1.9	+10.2	81.6
NICHD	+14.4	+18.8	+5.8	+5.6	+2.7	+12.1	71.3
NEI	+33.4	+23.2	+7.4	+4.4	+8.1	+11.1	114.4
NIEHS	+25.6	+21.7	+7.4	+66.9*	+8.8	+ 6.5	214.0
NIDR	+11.0	+5.7	+4.8	+4.2	+1.4	+ 9.6	43.3
NIA	+24.3	+52.5	+23.0	+8.1	+8.5	+14.8	204.5
Nine Smaller Institutes	(+16.8)	(+19.2)	(+11.3)	(+9.3)	(+3.2)	(+11.6)	(+86.3)
Total, Institutes	+12.6	+14.1	+8.6	+3.9	+2.0	+9.5	71.7
NHLBI Rank	8th	9th	11th	9-10th	6-8th	5th	9th

*Shift of the National Toxicology Program from NCI to NIEHS ($48.0) and the Diagnostic Radiology Grants from NIGMS to NCI ($4.4) in 1982 accounts for some of this difference.

Labor/HHS Appropriations FY 1983-1984

(Dollars in Millions)

Institutes	FY 1983* Continuing Resolution	FY 1984 ** President's Budget	% Change from FY 1983 Continuing Resolution
NCI	$ 983.6	$ 986.7	+ 0.3
NHLBI	622.7	637.7	+ 2.4
NIADDK	412.2	426.4	+ 3.4
NINCDS	295.7	301.6	+ 2.0
NIAID	273.6	289.4	+ 5.8
NIGMS	369.6	383.1	+ 3.7
NICHD	253.7	256.6	+ 1.2
NEI	141.6	142.3	+ 0.5
NIEHS	164.4	165.9	+ 0.9
NIDR	78.9	80.7	+ 2.3
NIA	94.0	99.4	+ 5.8
Subtotal	$3,690.0	$3,737.7	+ 1.3
DRR	213.8	201.8	− 5.6
FIC	10.1	9.2	− 10.9
NLM	46.0	49.6	+ 5.3
B&F	17.5	26.7	+ 3.8
OD, NIH	24.7	19.9	+ 13.7
Total	$4,002.1	$4,077.0	+ 1.9

*Continuing Resolution P.L. 97-377 provides funding through September 30, 1983.

**Revised April 5, 1983

STATEMENT OF DR. MARY JANE JESSE, PRESIDENT, AMERICAN HEART ASSOCIATION

Senator PROXMIRE. Our next witness is Dr. Mary Jane Jesse, president of the American Heart Association.

Dr. Jesse, I hope I pronounced your name correctly. It's nice to have you here.

Dr. JESSE. Thank you, Senator.

I'm the vice chairman of pediatrics and professor of pediatric cardiology at the University of Miami. And I'm here today on behalf of the American Heart Association, of which I am currently the president.

Let me first thank you and the committee for your support for biomedical research and application of new scientific knowledge to disease prevention, which you all supported so handsomely.

I'd like to make, this morning, four points and urge your support for appropriations in 1984 for $745 million for the National Heart, Lung, and Blood Institute, $354 million for the Institute of Neurological and Communicative Disorders and Stroke, and $55 million for the Library of Medicine.

The first point I'd like to make is that the NHLBI programs encompass, as you've just heard, 4 of the 10 leading causes of death in our country. Together, heart and cerebrovascular disease, chronic obstructive pulmonary disease, and atherosclerosis claim more than 1 million lives every year. They account for 53 percent of all the deaths in this country. In 1979, they accounted for $109 billion in direct and indirect costs and more than 27 percent of all the disease costs in this country.

So, just the scope of the NHLBI programs seems as if it ought to command a high priority.

The second point, thanks to a national effort led by the Institute, unparalleled progress has been made in the recent decades against these diseases. Basic scientific research carried out between the 1950's and the mid-1970's has brought new information on the process of atherosclerosis. And application of this knowledge has prevented more than 1 million deaths from heart attack and stroke in the last decade.

From 1968 to 1981, the death rate from cardiovascular disease declined by 32 percent in the United States. Stroke dropped 46 percent and heart attack 33 percent, a decline unequaled anywhere in the world.

Because of this decline in mortality, millions of dollars have been saved in costs, both direct and patient costs. Yet, despite this progress, cardiovascular disease continues to kill 1 million Americans every year.

The third point, in view of the remarkable progress that the NHLBI has made, one might conclude that this research institute merits our highest funding priority, certainly that it warrants support at levels to maintain its programs adequately. However, that's not been the case.

Although the NHLBI funding increased from $233 million in 1972 to $623 million in 1983, most of this increase was lost to inflation. The purchasing power in 1983 funding, in terms of 1972 dollars, was only $274 million, a real increase of only about 18 percent in 11 years.

NHLBI has consistently ranked low in its rate of funding increases, often no higher than ninth in the 11 institutes. In this year's President's budget as an example, the NHLBI placed 10th in rank of funding increases for the 11 institutes, an increase of less than 1 percent over the 1983 funding.

Based on the administration proposal, as you heard over and over again, the number of the NHLBI new and competing renewal awards will fall precipitously.

The fourth point, and maybe most important, is that advances in basic science don't occur in a smooth continuum. But when they do culminate to a peak, we can make very giant strides. Today we've got some examples of initiatives which will, we think, make great advances in diagnosis and treatment of heart attack, stroke, and vascular disease.

The examples: There are new, exciting imaging techniques to find arterial obstructions at low risk and low cost to patients; microsurgery within blood vessels by the use of directed laser beams; pursuit of important new findings on links between the central nervous system and hypertension.

I know that congressional appropriations committees are often asked to approve funding to "find the light at the end of the tunnel." We believe there are some lights already in place in the tunnel that includes cardiovascular disease. Unfortunately, they aren't bright enough to answer all our questions. What the the NHLBI needs is to have the generating power—the funding—stepped up.

Thank you, sir.

PREPARED STATEMENT

Senator PROXMIRE. Thank you, Dr. Jesse, very much. We will include your statement in the record.

[The statement follows:]

STATEMENT OF DR. MARY JANE JESSE

Mr. Chairman, I am Mary Jane Jesse and I am Professor and Vice Chairman of the Department of Pediatrics of the University of Miami School of Medicine. I appear before this committee on behalf of the American Heart Association -- its 120,000 voluntary leaders, 40,000 scientific members and more than 2 million program and fund raising volunteers. I currently serve as President. We are pleased to have this opportunity to provide the following comments.

We are deeply grateful to the Senate Labor/HHS Appropriations Subcommittee for your consistent support of federal programs in biomedical research and of the application of new scientific knowledge to ensure a healthier future for all Americans.

The National Institutes of Health is truly a "unique national resource." It represents a fund of scientific and technological capability that, since mid-century has brought our nation to a position of scientific leadership second to none in the world. The American Heart Association is pleased that its own programs in biomedical research, education and prevention also have contributed to this leadership.

The AHA shares many common attributes with the National Heart, Lung and Blood Institute. We were both established in 1948 -- AHA by the voluntary association of scientists and lay persons and the NHLBI by act of Congress. We are proud to have been in the forefront of those who urged that the federal commitment to the prevention of premature death and disability from cardiovascular diseases be given statutory standing. Over the 35 years that have ensued, we have supported the extension of this authority by Congress and have worked closely with the NHLBI as it developed the program mechanisms to carry out its mandate.

The NHLBI program encompasses four of the nation's ten leading causes of death, diseases that together account for 53 percent of all mortality in the United States. Together these diseases claim more than one million American lives each year. Together the direct and indirect cost of these diseases in 1979 totaled $103 billion -- more than 27 percent of all disease costs in our nation.

These facts argue effectively that the magnitude and scope of the health problems addressed by the NHLBI are such that they cannot be overlooked by those who determine our nation's health policy. Unless we make progress against these major killers, our advances in health will continue to be limited.

Many interest groups come before the appropriations committees of Congress to ask for more funds in order to "find the light at the end of the tunnel." In the case of the NHLBI, we believe that some lights have already been installed in the tunnel. Not that they are so illuminating that we can see the answers to all our questions, but lights nonetheless. What we believe the NHLBI needs now is to have the generating power -- the funding -- stepped up in order to keep these lights burning as brightly as the state of our science and the ingenuity of our scientists will allow.

ince 1968 -- due in large part to the scientific advances made in the 1950's and 1960's -- the NHLBI has demonstrated an unparalleled program effectiveness. The death rate from coronary heart disease has decreased by 32 percent. The death rate from stroke has plummeted by 46 percent. The rate of death from all cardiovascular diseases has declined by 33 percent. During this same period the death rate from all other disease has fallen by only 13 percent -- a clear indication that this progress is specific to cardiovascular diseases and is not a general health trend.

It has been estimated that this decline in death rates has resulted in the saving of more than a million American lives. With this savings in life also comes a significant savings in tax dollars and in private and industrial health expenditures. Thus the cost-effectiveness of federal investment in NHLBI programs is amply evident.

Much more progress and new potentials for application of knowledge and technology are at hand or are on the horizon. Many promising new initiatives that are now ready for study or implementation have been deferred only by a lack of funding. To cite a few:

- New radiological imaging techniques will permit us to identify -- at reduced hazard to the patient and at much less cost -- the size and location of coronary artery obstructions. This could mean earlier and more effective treatment of heart attacks.

- Two recent NHLBI studies show that individuals with mild hypertension whose electrocardiograms have abnormalities are at high risk of death if treated with drugs commonly used in hypertensive therapy. It is imperative that studies of this relationship and identification and the careful treatment of these patients be undertaken soon.

- Dramatic new findings have emerged regarding the role of the central nervous system in the control of blood vessels as a factor in the causation of hypertension. Pursuit of these new techniques in the treatment of early hypertension should begin immediately.

- We must follow experimental techniques that could relieve coronary obstruction at much less cost and risk to patients than coronary bypass surgery. These include use of the enzyme streptokinase to dissolve clots that develop in the early stages of myocardial infarction, and microsurgery within blood vessels by means of directed laser beams.

- New techniques now allow the use of monoclonal antibodies in blood tests that can identify individual and familial susceptibility to rheumatic fever. Such early identification can trigger therapy to prevent rheumatic fever and rheumatic heart disease.

- Recent evidence indicates an increase in the incidence of cardiomyopathy, a disease that can damage the heart muscle to such an extent that the only therapeutic approach is a total heart transplant. We need to investigate the reasons for the increased onset of this disease and for the progression of cardiomyopathy.

- There is a marked increase in the number of premature infants born with cardiac defects. In a recent study of 4,674 cases, 982 babies (21 percent) were found to have a congenital heart defect. Among those with this defect, 206 infants (21 percent) failed to respond to any treatment -- including surgery -- and died as a result. This emphasizes the need for further research, and for the effective prenatal education of women.

The American Heart Association is convinced that in terms of the magnitude and scope of the health problems it addresses, in terms of the high rates of morbidity and mortality from these diseases, in terms of the huge expense in treating these diseases in their acute and chronic stages and in terms of the remarkable progress made in preventing premature death and disability -- the NHLBI merits the highest priority of support by the administration and the Congress.

However, when we look at the long term patterns in funding for NHLBI, there is no indication that any such priority exists -- quite the opposite, in fact. Although current dollar funding for the institute increased from $233 million in 1972 to $633 million in 1983, most of this increase was lost to inflation. The purchasing power of 1983 funding in terms of 1972 dollars was only $274 million -- an increase of less than 18 percent in 11 years!

In reviewing the rate of annual increases in funding for the various institutes of health over recent years, NHLBI has consistently ranked very low -- often no higher than 9th among the 11 institutes. And this is despite the fact that Congress has mandated many additional NHLBI programs since 1972. An indication that this trend of low priority increases is not improving is the fact that in the President's Budget for 1984, NHLBI was placed 10th in rank of funding increases for the 11 institutes -- an increase of less than one percent!

Funding shortfalls since 1979 have been especially serious. Based on the President's 1984 Budget, new and competing research grant awards would decline from 942 in 1979 to 550 in 1984 -- a drop of 42 percent. Since 1978 many new NHLBI program mechanisms -- Clinical Trials, National R & D Centers, the contract-supported research and development programs -- have been blocked from implementation or have declined for lack of adequate funding.

Unless the Congress substantially increases the level proposed for biomedical research funding in 1984, the NIH can support less than 3,700 new and competing research grants -- his would be only 63 percent of the 5,000 grants which was to constitute the minimum necessary to sustain NIH research productivity. Based on this funding, the NHLBI could fund only 550 grants in 1984 -- 200 below its five-year average of 760 -- and its award rate would fall to about 26 percent.

Due to the low level of funding increases since 1972, the NHLBI extramural program has grown only 1.5 percent per year in constant dollars. The award rate for new and competing research grants has fallen from 63 to 37 percent. Perhaps as a result of inadequate funding, the percentage of physicians among research grant applicants has fallen from 51 to 28 percent.

aced with funding shortfalls and mandated percentage cuts in programs, the NHLB Advisory Council has had to give serious consideration as to which of its programs it can discontinue, or how it must apportion damaging cuts in all its programs in order to ensure that some of its programs can function at adequate levels.

These are clearly "survival" choices -- choices that should not be made.

In order to preserve its research effectiveness, to maintain its balanced, mandated program and to stabilize the future of biomedical research by inducing bright young scientists to enter a career in research, we urge this committee to accord a higher priority to NHLBI funding in 1984 and beyond.

The American Heart Association also wishes to urge increased funding for the National Institute of Neurological and Communicative Diseases and Stroke. Although death rates from stroke are declining, more than two million Americans are now afflicted with devastating disability. We urge increased support of NINCDS research programs that have brought noteworthy advances, such as noninvasive scanning technology and new surgical techniques that bypass arterial blockages, close arterial ruptures and permit surgical procedures ithin the deep brain. If the current momentum can be continued, many strokes can be prevented -- saving lives, years of disability and millions of dollars in long-term health care.

We again wish to point out our support for increased funding for the National Library of Medicine. This important knowledge base and communication system has served to advance the generation and distribution of scientific information in our nation. Its programs must be maintained.

We also urge increased support of the Laboratory Animal Sciences and Primate Research Program of the Division of Research Resources, NIH. Without these programs -- through which ew doors of knowledge are opened for biomedical science -- many research "breakthroughs" would not have been possible.

These programs have been subject to criticism from certain interest groups whose mission is to deny biomedical scientists the use of animals for necessary laboratory research and testing. Last Sunday a coalition of animal welfare groups organized a public demonstration at four of the Primate Centers operated by the NIH. Their avowed purpose is to seek closure of the centers by public demonstrations and by opposing allocation of federal funds to continue their operation.

The American Heart Association is opposed to these efforts, and wishes to endorse continued support for the LASPR programs within NIH. We support efforts to ensure the humane treatment of research animals, but we oppose efforts that would deny the appropriate and necessary use of laboratory animals to biomedical research.

The American Heart Association recommends that there be appropriated for Fiscal Year 1984 the following amounts:

- National Institutes of Health -- $4,800,000,000
- National Heart, Lung and Blood Institute -- $745,000,000
- National Institute of Neurological and Communicative Disorders and Stroke -- $354,000,000
- National Library of Medicine -- $55,000,000
- NIH, Division of Research Resources, Laboratory Animal Sciences and Primate Research -- $33,000,000

The American Heart Association also endorses the administration's recommendation for appropriation for Fiscal Year 1984 for two programs in the Office of the Assistant Secretary for Health. We commend the President for recommending increased funding for these programs and urge that these be no reduction from the following amounts:

- Office of Smoking and Health -- $3,000,000
- Office of Health Information and Health Promotion -- $3,500,000

The American Heart Association is grateful that these comments will be considered by the Committee on Labor and Human Resources.

B0422

STATEMENT OF DR. PAUL A. McCURDY, CHAIRMAN, PUBLIC EDUCATION COMMITEE, AMERICAN SOCIETY OF HEMATOLOGY

Senator PROXMIRE. Dr. Paul McCurdy, public education committee, American Society of Hematology.

We're happy to have you, Dr. McCurdy.

Dr. McCURDY. Mr. Chairman, on behalf of the American Society of Hematology and its more than 3,000 members, I'd like to thank you for the opportunity to present testimony before this subcommittee in conjunction with the legislation for fiscal 1984 appropriations for the National Institutes of Health.

I am Dr. Paul R. McCurdy, director of the Washington region of the American Red Cross Blood Services and professor of medicine at Georgetown University School of Medicine.

I am here today as chairman of the public education committee of the American Society of Hematology. This society is the only national organization of hematologists and is made up of physicians and biomedical scientists who are concerned with research, patient care, and teaching activities as they relate to blood.

Before presenting our views about the legislation, I would like to express our gratitude to you, Mr. Proxmire, and to your associates for your strong support and efforts on behalf of biomedical research and hematology. We greatly appreciate your longstanding commitment to the programs of the National Institutes of Health.

Both basic and applied research in hematology, much of it by members of our society, have greatly influenced progress in many medical disciplines.

Our written testimony summarizes only a few examples relating to hereditary diseases, leukemia, blood and plasma resources, and anemia secondary to such disorders as arthritis and kidney disease.

Although funds for research are of paramount importance, we urge that they not be provided at the expense of support for research training, clinical trials, and specialized research centers.

Please maintain the past commitment to encourage training in biomedical research and hematology and provide investigators for the future.

Clinical trials bring fruits of laboratory and more basic clinical research to the bedside. Specialized research centers provide a critical mass of investigators and facilities targeted to topics of special interest.

The recommendations to the Appropriations Committee in the U.S. Senate are:

For the National Heart, Lung, and Blood Institute, a funding level of at least $695 million for fiscal year 1984.

For the National Institute of Arthritis, Diabetes, Digestive, and Kidney Diseases, at least $475 million.

For the National Cancer Institute, at least $1,300,000,000.

For the National Institutes of Health as a whole, at least $4,491,000,000 for fiscal year 1984.

And bill report language, as discussed in our formal testimony, which stresses that blood research is carried out in many NIH institutes, and particularly in NHLBI, NIADDK, and NCI, recognizes this wide ranging research effort and urges its continuation.

Thank you for your past support for hematologic research.

I'd be glad to answer any questions you might have.

PREPARED STATEMENTS

Senator Proxmire. Thank you very much, Dr. McCurdy. We very much appreciate your presentation. Your statement will be included in the record at this point, along with other statements submitted on appropriations for the National Heart, Lung, and Blood Institute.

[The statements follow:]

STATEMENT OF DR. PAUL R. MCCURDY

Mr. Chairman and Members of the Committee:

On behalf of the American Society of Hematology and its more than 3,000 members, I thank you for the opportunity to present testimony before this Subcommittee in connection with the legislation for the Fiscal 1984 appropriations for the National Institutes of Health.

I am Dr. Paul R. McCurdy, Director of the Washington Region of the American Red Cross Blood Services and Professor of Medicine at Georgetown University School of Medicine. I am here in my role as Chairman of the Public Education Committee of the American Society of Hematology. This society is the only national organization of hematologists and is made up of physiciens and biomedical scientists who are concerned with research, patient care and teaching activities as they relate to blood.

Before presenting our views about this legislation, I would like to take a moment to express our gratitude to you, Mr. Weicker, and to your associates for your strong support and efforts on behalf of biomedical research and hematology. We greatly appreciate your long-standing commitment to the programs of the National Institutes of Health.

A few minutes would be in order, I believe, to summarize a small fraction of the recent exciting and important advances that have been made in the research programs related to hematology, blood diseases and blood resources.

1. Recombinant DNA and cloning technology has been used to produce a clotting factor IX material. This shows promise in telling us more about that clotting factor, deficient in one form of hemophilia, hemophilia B, and how it is produced. The possibility exists that a factor IX clotting protein will be made in vitro and be free of contamination by the viruses of hepatitis and even the as yet unknown agent producing Acquired Immunodeficiency Syndrome (AIDS). Similar research is being done for Factor VIII, the clotting factor lacking in patients with hemophilia A. The number one problem in hemophilia care at present is availability of the replacement antihemophilia factors; the second greatest problem is safety of therapy because of the transmission of diseases such as hepatitis and possibly AIDS by these treatment materials. At a recent meeting, information was presented that suggested that AIDS was the next most common cause of death in patients with hemophilia, after bleeding. This is notwithstanding the small number of patients with hemophilia who have been found to have AIDS (10). Not only are some members of the Society involved in basic research in this area

but other members are treating patients with blood and blood products who then may be at risk for becoming ill with AIDS. The importance of basic research leading to the production of clotting factor concentrates in the test tube, free of infectious agents, is well known to them. Many Society members will be involved in the clinical studies necessary to determine if these test-tube synthesized clotting factors are useful and safe.

2. Many of the techniques of studying the lymphocyte and its subsets have been developed by members of the American Society of Hematology. These techniques and the knowledge obtained thereby are being used to investigate AIDS in the hope that improved methods of prevention and treatment can be found. When these basic studies were begun, AIDS was unknown; the goals of the studies were better understanding of certain forms of leukemia and of the mechanisms by which the body defends itself against viruses and other foreign agents. These same studies have opened doors into better understanding of the organ transplantation process as well.

3. Last year in these hearings, my colleague, Dr. Ernst Jaffe, cited studies of the switch from the production of fetal hemoglobin in the uterus to that of adult hemoglobin around the time of birth. Since that time, an exciting discovery has been made and reported in preliminary fashion. A drug has been found that "turns back on" fetal hemoglobin production in older patients and shows promise for the treatment of both Cooley's anemia (thalassemia) and sickle cell anemia. These diseases affect the production or composition of only adult hemoglobin so that the defect may be by-passed when fetal hemoglobin synthesis, predominant in the uterus is switched back on. Individuals with these diseases do not become ill until some months after birth when hemoglobin production is converted from the fetal form to the adult form. Should this approach or one like it prove effective, the dependence of the patients on blood transfusions will be significantly reduced. Furthermore, these studies will undoubtedly give us greater insight into how and why genes turn on or off at certain times of life or in some tissues but not others.

4. Anemia is a significant problem in many chronically ill patients such as those with end-stage kidney disease or arthritis. Through the years, NIH-sponsored research undertaken by members of our Society has pin-pointed a key role for a deficiency of the hormone called erythropoietin in the cause of anemia that accompanies severe kidney disease. Preliminary experiments suggest that this anemia can be improved by administering this red cell producing hormone, but its supply is so small as to preclude any large scale treatment. Current studies are aimed at producing enough of this hormone to treat such patients without requiring blood transfusions.

5. Although the "Orphan Drug" law recently passed may have some benefit in the development and production of preparations of trace plasma proteins, research supported by the NIH will probably play the dominant role. Dr. Doris Menache-Aronson, Chairman, Blood Diseases and Resources Advisory Committee, NHLBI, recently stated, "The opportunity to develop potentially new plasma derivatives is enormous... Unfortunately, the plasma fractionation industry is technically and scientifically static, innovations are rare, and scientific leadership is elsewhere....Within the last 15 years, only one new plasma derivative has been introduced. (and that was) Developed by accident, the product is currently being used....(but) No clinical trial has been undertaken to prove its efficacy....." Two such materials in preparation now are anti-thrombin III, deficiency of which results in clots in blood vessels, and C1-esterase inhibitor, deficiency of which results in a rare hereditary disease with potentially fatal hives. Red Cross research laboratories, supported in part by NIH funds, are heavily involved in this area.

6. Members of our Society are doing both basic and applied therapeutic research on leukemia and other cancerous blood disorders. Federal support has resulted in great advances in these areas in the past few years. Recently, the outlook for acute granulocytic leukemia in adults has improved from 3-6 months for all to about 50% doing well after 5 years. The use of bone marrow transplantation for some children and young adults who do not respond well to other therapy is experimental at present but shows promise. Previous support has resulted in marrow transplantation becoming standard therapy for some patients with aplastic anemia -- the ability of their bone marrow to make blood cells has been destroyed. Earlier in this testimony I discussed thalassemia or Cooley's anemia. I can report that recently this disorder has been successfully treated by bone marrow transplantation in two patients with a very severe form of the disease. Although available for only a select few who have tissue (HLA) matched brothers or sisters, this therapeutic feat is very exciting. Basic research in the past by members of our Society resulted in the discovery of the HLA system -- HLA stands for Human Leukocyte Antigen.

7. The massive research effort directed toward sickle cell anemia and related disorders, begun about a decade ago, has led to a better understanding of the disease process, from its genetic control to its clinical manifestations. In particular, better understanding of the role of infection and methods of coping with it has greatly improved the outlook for a newborn child with sickle cell anemia. Until the last few years, there was a high probability that such a child would die of overwhelming infection by age 4-6. Ascertaining that fact led to the

development and introduction of a bacterial vaccine that has proved very effective in preventing one of the more common infections in these patients. Information on the tolerance of such patients to blood transfusion may lead to better matching procedures to avoid later complications of transfusion.

8. Red blood cell enzymes have been studied for some years and the information obtained has been applied to a number of non-red cell disorders. For example, recent research into a key enzyme for sugar metabolism has led to a better understanding of an hereditary disease with abnormal and excessive storage of glycogen, a reserve form of sugar. Application of another new technique, the production of a special type of antibody called "monoclonal", has allowed precise definition of specific subunits of this enzyme, some of which are abnormal in the disorder affecting muscle.

These few examples, I believe, demonstrate the value of supporting research in Hematology. I should like to point out that many of the studies done by hematologists have far reaching consequences outside of blood diseases. It is relatively easy to obtain a sample of blood, even repeatedly, from the same individual. Circulating blood cells are living and functioning like other cells in the body. Studies using blood cells can give and have given great insight into the function, growth and death of cells in many other organs. At a recent meeting of specialists in many different areas, I was struck by the frequency with which new advances in other fields were either based upon earlier studies involving blood cells or were in parallel with such studies. Many diseases, previously enigmatic, are now seemingly based upon altered immunity, such that the immune system seems to attack organs in the unfortunate patient. Hematology, the study of blood, remains in the forefront of research affecting many organs and tissues. The blood, indeed, perfuses all organs; disease of the blood affects most other tissues and disease of most tissues affects the blood.

Although the National Heart, Lung and Blood Institute (NHLBI) supports the largest portion of blood research, the National Institute of Arthritis, Diabetes, Digestive and Kidney Diseases (NIADDK) and the National Cancer Institute (NCI) also support research into blood disorders of interest to our society. Although 80% of the Federal funds for blood research come from these three Institutes, it is worth noting that 20% comes from the other eight Institutes. Because of the wide applicability and importance of blood research, we would very much like to see this multiplicity of support mechanisms for it continued. We hope that you will include in your bill report a recognition of the multiple programs of support for blood research at the NIH, and encouragement for it to continue.

I would now like to turn to a consideration of the critical need to continue training programs in research. The NHLBI and the NIADDK have been able to maintain research funding at its present level only at the expense of other programs, such as training for research. This, in our belief, is a short-sighted borrowing from the future akin to "eating one's seed corn". In the recent past, the National Research Council recognized this need: "At the center of Federal policy, there should be an irreducible number of trainees who are supported in the basic disciplines, regardless of fluctuations in demand for short-term research needs...The need for a steady infusion of young, well-trained and creative scientists into research positions in the biomedical and behavioral sciences is absolutely essential for maintaining the vigor of the national research endeavor". Research training grants and fellowships provide, at modest cost, opportunities for those interested in pursuing academic and research careers to obtain and use the necessary training for them to carry out their own original ideas. Although some leave research for financial or intellectual reasons, many continue on in academic or clinical research, making immense contributions to the future health of the country. At one time, I believed I would enter medical practice; instead, I seized an academic opportunity and through the years have continued in a research and teaching role. This illustrates the difficulty of predicting in advance what a future career in medicine will produce. Please, therefore, do not discourage these young investigators further by reducing, directly or indirectly, the support for research training. Be reminded that the costs of such training include not only the meager stipends for the trainees themselves, but also the expenses in obtaining supplies and materials for their use. Institutional support, therefore, is as essential as the stipends provided for the researchers-in-training. Please maintain the commitment that has been made in the past to provide a continuing supply of future biomedical research scientists for this generation and the next.

Finally, I would like to emphasize again our Society's concerns about government funding and support for biomedical research and training, restating that the potential is for adverse effects over the short and long term if adequate resources are not provided. Fortunately, this Committee and other members of the Congress have recognized these hazards in the past and have taken the necessary action.

The American Society of Hematology would like to join with other organizations represented here today in urging that at least $695 million be appropriated for the NHLBI for Fiscal 1984, $475 million for NIADDK, $1.3 billion for the NCI, and $4.491 billion for the NIH as a whole.

My colleagues and I in the field of Hematology thank you, Mr. Chairman, and the members of your Subcommittee for your kind attention to our presentation. We can assure you that the blood research work proposed for the near and distant future will be done by those who have been, and will be, trained to do it. We applaud and sincerely thank you again for recognizing the past accomplishments and for providing us with the means necessary to go forward.

I will be pleased to answer any questions you may have.

RECOMMENDATIONS: APPROPRIATIONS

The recommendations to the Appropriations Committees of the U.S. Senate and the U.S. House of Representatives by the American Society of Hematology are:

1. For the National Heart, Lung and Blood Institute, a level of funding of at least $695 million for Fiscal Year 1984;
2. For the National Institute of Arthritis, Diabetes, Digestive and Kidney Diseases, a level of funding of at least $475 million for Fiscal Year 1984;
3. For the National Cancer Institute, a level of funding of at least $1.3 billion for Fiscal Year 1984;
4. For the National Institutes of Health, a level of funding of at least $4.491 billion for Fiscal Year 1984;
5. And "bill report language" which stresses the fact that blood research is carried out in many NIH Institutes, and particularly in NHLBI, NCI, and NIADDK, and that wide-ranging research effort is recognized and should continue.

Thank you for your past support for hematological research.

STATEMENT OF DR. ELIOT CORDAY, CLINICAL PROFESSOR OF MEDICINE, UNIVERSITY OF CALIFORNIA, LOS ANGELES, SCHOOL OF MEDICINE, SENIOR RESEARCH SCIENTIST, AND MEMBER OF THE BOARD OF DIRECTORS, CEDARS-SINAI MEDICAL CENTER, LOS ANGELES, CALIF., PAST PRESIDENT, AMERICAN COLLEGE OF CARDIOLOGY

Mr. Chairman, I appreciate the opportunity of providing testimony concerning the '84 annual budget of the National Heart, Lung and Blood Institute (NHLBI) and about strategies for achieving and maintaining a balance of program mechanisms for protecting and augmenting the choice and number of appropriate research grants awarded by the Institute.

It is again a pleasure for me to report to you and your dedicated committee on the cardiovascular health of the nation. I am the author of 475 publications and six textbooks on original research studies. I have functioned in many capacities:- wearing the hat of a health planner, member of the National Advisory Council of the NHLBI, and in addition, as an educator, active research worker, and practicing cardiologist. First, I bring you a condensed report containing some good news, but also, I regret, sad tidings.

The good news is that the United States continues to be regarded as the predominant world center in heart, lung and blood diseases. The great advances were made possible by the notable long term programs funded through our revered National Institutes of Health and the freedom for all to pursue their own imaginative scientific precepts in competition, yet share their immediate findings in massive, coordinated peer review.

Other good news is that the cardiovascular mortality rate in the USA which decreased more than 30% in the last 30 years, declined most dramatically in the last decade. In a recent mission to the Balkans where I had the opportunity to compare medical experiences, I learned that the Hungarians, Bulgarians and Romanians were alarmed that their mortality was increasing as ours declined. In our joint staff conferences we attempted to pinpoint the possible reason for these statistical differences. It became apparent that although we both strive to control the same coronary risk factors, our national professional objectives are primarily aimed at other major targets with different motivations. In the United States we are organized in depth to achieve faster comprehensive delivery of emergency medical services for the treatment of the coronary victim. Balkan officials report their coronary victims are apt to delay emergency care for hours because they seem to lack confidence in the skill and proficiency of their local hospitals and ambulance procedures. Also, the U.S. system is unique because it recognizes that if the heart should arrest, a delay in onset of resuscitation of more than 4 minutes could be disastrous and therefore, the victims must be skillfully resuscitated within these time constraints even en route to the hospital. Furthermore, in the USA up to 200,000 coronary bypass operations are being performed electively per year with an operative mortality of only 1-2% and coronary bypass can both prolong life and improve life style. By comparison, the cardiologists in the Balkans consider the mortality too high for them to recommend coronary bypass to their patients, so that now their governments have turned to the American College of Cardiology asking them to help train surgical teams from their country consisting of five specialists each year. It was my impression that their rising cardiac mortality rate might be corrected if their emergency coronary care service and coronary surgical techniques were improved.

The sad tidings:

1) Despite these gains, heart disease continues to be our biggest killer in the USA, still claiming over one million lives a year, and it is also our worst crippler (Fig. 1). Many of these deaths are unexpected, and occur in the prime of life.

2) The total economic cost of cardiovascular disorders is estimated to be in excess of $60 billion annually. Of this amount:

$20 billion represents health expenditures

$10 billion, productivity costs due to illness

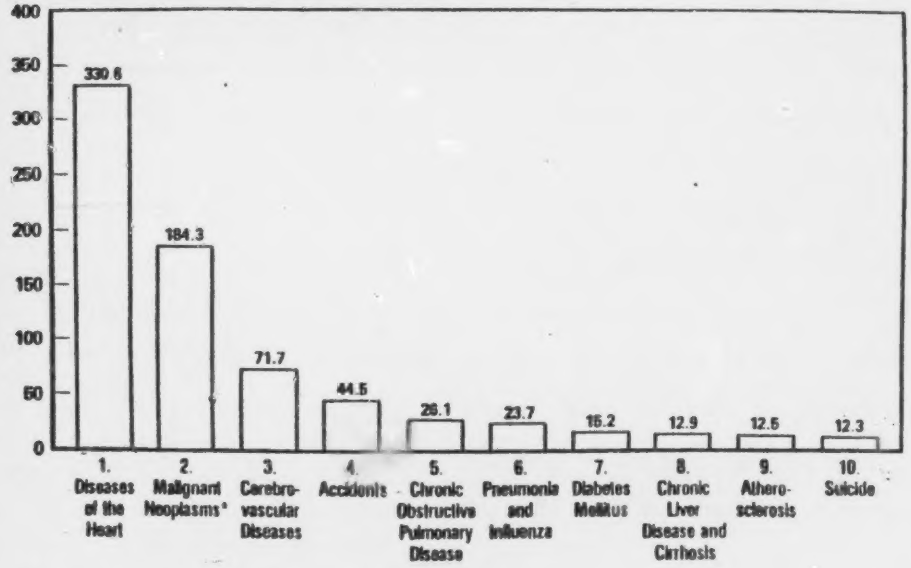
$30 billion, potential productivity loss due to early death.

This $60 billion accounts for more than one-fifth of the total cost of illness in the United States. The costs of palliative repair are much too expensive.

Transplants and artificial heart implants are not the answer. Prevention must be the ultimate objective, and this should be attainable by public health measures as was the miraculous conquest of poliomyelitis, tuberculosis, infant diarrhea and numerous other diseases in the four past decades.

FIGURE 1

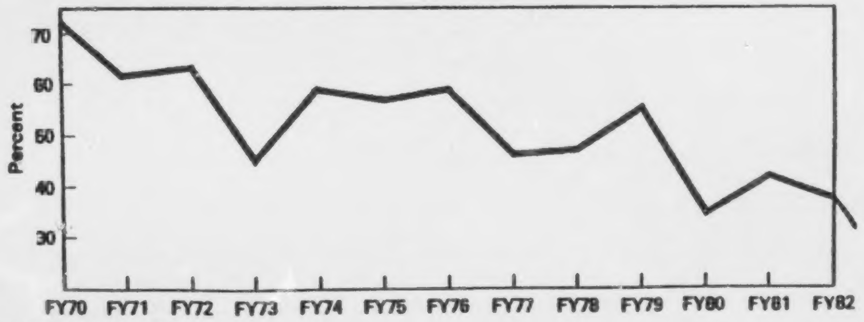
Ten Leading Causes of Death:* Death Rates, U.S., 1981 (Rates per 100,000 Population)



*Including neoplasms of lymphatic and hematopoietic tissues.

FIGURE 2

NHLBI Competing Research Project Grants:* Percent Funded, Fiscal Years 1970-1982



*Includes R01, R23, P01 grants.

†Reflects release of fiscal year 1973 impounded funds.

‡Includes unfunded approvals carried over from previous years which were funded within a specific year.

3) Now the message from the recently completed ten year multiple risk factor intervention trials (MR FIT) seems to leave the practitioner confused for it seems little can be done to affect the course of the arteriosclerotic process even if an attempt is made to bring risk factors under control on a mass scale. Other recent research investigations suggest that we have a few distinct leads as to the causation, and this enourages us to intensify our search for the answers regarding long term protective treatment. If the obstructive arteriosclerosis process can be fully understood and controlled, prevention might become possible. I will include in my testimony a few clues that could provide more promising research thrusts. Our future goals must include further incisive research on the etiology and pathogenesis of arteriosclerosis, and we must look for imaginative new avenues of investigation for this dreaded disease process.

4) Our research effort in cardiovascular disease is being slowed down because of cutbacks: The serious slowdown in research can also be appreciated from the fact that the NHLBI projected that only 34% of approved projects might be funded in FY '83 compared to about 75% in FY '70 (Fig. 2). Imagine how we have damaged the hopes of frustrated, dedicated research workers, gradually stopping or discouraging them in their work during the past 6 years. We have crushed carefully thought out research plans and turned off the enthusiasm of well trained scientists. If we increase the NHLBI budget to include an additional $125 million for fiscal year '84 for the conquest of arteriosclerosis, our scientists who were trained at a high public expense will again have the opportunities to score significantly in the conquest of our nation's most crippling and fatal disease. I believe it is not too late to get the dedicated scientists back to their laboratories and restore challenging research investigations for the benefit of mankind.

NEW INVESTIGATIVE PROGRAMS WE CONSIDER MOST PROMISING:

My colleagues, Drs. William Ganz, Nemat Borhani, Alan Fogelman, and Mayer Davidson, have helped me prepare a list of new research concepts. They are as follows:

I. NEW TECHNOLOGY FOR THE STUDY OF CAUSATION AND TREATMENT OF OBSTRUCTIVE ARTERIOSCLEROTIC PROCESSES:

(a) Blood platelet accumulation leading to clotting. The actual biochemical mechanism which causes abnormal blood clotting (thrombosis) can now explain the all important participation of platelets in thrombosis. It, for the first time, incriminates a chain of interaction of recently explored chemical pathways by which platelets are stimulated to adhere and aggregate and to release their granular contents to form clots. The role of prostaglandins in arterial wall metabolism has been clearly incriminated because this natural substance strongly influences the behavior of the arterial wall, the cells in the blood, and also the very important clumping agent, arachadonic acid, traversing the arterial lumen. These are thought to be the most potent substances known for aggregating or dispersing the platelets, yet some simple medications such as aspirin and dipyridamole are being examined for their potential to prevent the complication of atherosclerosis because they are known to interfere with these life threatening metabolic mechanisms associated with excessive blood clotting. Also, recent publications prove our discovery that prostaglandin can reduce infarct size.

(b) Immunology. Many clinical experiences cause us to question whether immunologic malfunction can provoke atherosclerosis. For instance, why did an 18 year old heart transplant recipient with a 19 year old donor's heart succumb to galloping arteriosclerosis within 6 years after transplant? Could this type of arteriosclerosis be considered a rejection phenomenon to the new heart or reaction to medication used to reduce the immunologic reaction to the transplanted heart?

(c) Endocrinology. The fact that women live approximately 11 years longer than men, and that their atherosclerotic process becomes evident only after the onset of their menopause, should provide an important endocrine lead about the causation of obstructive arteriosclerosis. Is there some hormone or antihormone factor that needs to be discovered which accounts for the earlier onset of arteriosclerosis in the male? It could be a difficult problem because ingestion of female hormones does not protect the male with accelerated arteriosclerosis.

(d) Virus etiology of arteriosclerosis. Many studies point to a virus as an etiologic cause of the obstructive arteriosclerotic process.

(e) Diabetes as a cause of arteriosclerosis. Why the strong association of diabetes with accelerated arteriosclerosis? Could the arteriosclerosis be due to a correctable metabolic error in the endocrine-pituitary complex?

(f) Why are the obstructive lesions so often localized and self-limited? Dr. DeBakey recently reported his angiographic studies on some 15,000 patients followed for several decades, with severe obstructive arteriosclerotic lesions that were often confined to the same regional vessels in the years of followup. After surgical bypass, the obstructive involvement seemed to stand still for years, suggesting that the arteriosclerosis process is not created by a generalized progressive infiltrative process of the tissues with cholesterol and lipids as we have been taught to believe.

g) Metabolism of the arterial wall itself. There must be some degenerative disease process distorting the metabolic process of the arterial wall itself which causes the buildup of cholesterol material and other substances which induce the obstruction in the artery. We need to know more about the biochemical processes of the arterial wall and how to control it.

NEW DYNAMIC CONCEPTS FOR THE CONTROL OF ARTERIOSCLEROTIC HEART DISEASE

STATEMENT OF ALAN FOGELMAN, M.D., Professor and Chief, Division of Cardiology, UCLA School of Medicine - He reports on what might possibly be considered the most exciting, world shaking breakthroughs in molecular biology, cell biology, biochemistry and genetics, providing entirely new concepts on etiology of atherosclerosis, including cloning and gene splitting engineering. Recently, there have been a number of major breakthroughs in the biological sciences that are likely to result in important new information on atherosclerosis, assuming there is adequate funding to pursue these new avenues of research. These are discussed further in technical detail in the appendix.

I. LYSIS OF AN ACUTELY OBSTRUCTED CORONARY ARTERY: An area of tremendous scientific interest is the relatively noninvasive technique developed to lyse (dissolve) the blood clot once it forms in a coronary artery to cause a full fledged coronary attack. Unless this clot formation is dissolved or removed within a 3-hour period, it can lead to destruction of the heart muscle (myocardial infarction). To be successful, this situation requires full scale emergency treatment which has recently been tested at many medical centers. It consists of the immediate infusion of a thrombolytic agent (such as streptokinase which dissolves the clot) by way of a catheter inserted via the coronary arteries aimed directly at the point of the occlusion. It has been shown to wash out the blood clot and limit the size of the infarct within minutes to hours. However, other investigators have shown they can dissolve the clot more simply by administering the drug intravenously. Further cooperative studies are seriously needed to determine which techniques should be adopted on a national scale as standard therapy.

II. RETROPERFUSION - A NEW EMERGENCY METHOD TO REDUCE HEART DAMAGE BY SUPPORTING THE REGIONAL CIRCULATION OF AN OBSTRUCTED CORONARY ARTERY WITH A MECHANICAL ASSIST PUMP: A promising new technique provides circulatory assistance via a retroperfusion catheter. This tube can be inserted externally to pump blood from a coronary victim's femoral artery directly into the coronary veins via the jugular vein in the neck to bypass the obstructed clotted coronary artery. It pumps the patient's own arterial blood past the blocked coronary segment. The entire emergency system can be set up within a 12-minute period after a victim arrives at the hospital. Because the blood is cooled 10°C it protects the jeopardized heart muscle from deteriorating. At the same time, streptokinase, an enzyme, can also be pumped in to dissolve the obstructing coronary clot. When the clot dissolves, within a few hours, the catheters can be removed and the patient can then be discharged from the hospital.

III. CORONARY ANGIOPLASTY: There is a great deal of interest at the present time in a procedure in which a balloon catheter is inserted into a segment of coronary artery narrowing and then inflated to break up the coronary obstruction. The present technique is rather limited because only one coronary artery can be opened in a single session. However, several prominent investigators are planning to perform this intervention on 2 or 3 major arteries at one session while supporting all the other major coronary circulations with the retroperfusion technique described in Section II. This will probably permit a larger number of patients to become candidates for this inexpensive angioplasty procedure.

IV. NONINVASIVE IMAGING OF THE BEATING HEART WITH SPACE AGE TECHNOLOGY: Computer-enhanced imaging utilizing (a) ultrasonics, (b) nuclear scintigraphy, (c) digital subtraction angiography, (d) nuclear magnetic resonance are being adapted from space age technology to provide simultaneous images and calculations of coronary blood flow of the heart muscle that have never before been attainable. These imaging techniques can be computerized to quantitate and characterize normal and abnormal blood flow and perfusion defects of the heart tissue without invading the chest. These simplified techniques open the door to low cost, noninvasive, repeatable, clinical studies that can be developed for an inexpensive outpatient approach to screen the cause of the patient's chest discomfort or even localize an obstructive process which might need surgical intervention. When this dramatic technology is perfected, it promises to reduce health care costs considerably, because it will require less expertise, and can be performed on an out patient basis.

THE URGENT NEED FOR A MORE REALISTIC BUDGET FOR OUR NATION'S GREATEST KILLER: In February 1966 I presented Senator Lister Hill, Chairman of the Senate Appropriations Committee, the report of a Bethesda Conference Committee of the American College of Cardiology which concluded that if a nationwide training program could train the attendant nurses of the 6,000 major hospitals of the USA in the new aggressive principle of coronary care we could save 45,000 lives per year. The report recommended that a $27 million budget could establish programs across the nation. This appropriation was passed quickly, and within three years Federal support could be turned off because the primary training mission was accomplished, and volunteer organizations were then capable of continuing the training task themselves.

In 1965, Congressional committees, on Dr. DeBakey's advice, voted $15 million a year to develop circulatory assist and artifical heart programs and also 9 specialized centers called myocardial infarction research units (MIRU) across the nation. Within a short period these centers started to provide dynamic lifesaving techniques to treat cardiogenic shock and salvage the acutely injured heart muscle. These units have since evolved into the Specialized Centers of Research (SCOR) in ischemic heart disese to conform with DeBakey's original concept; most of the original 9 major centers are still in operation, performing dramatic interventions for treatment of the critically ill cardiac patient who would otherwise die or be seriously crippled. Many heart attack victims used to die of cardiogenic shock, but now we see that very few acute coronary patients succumb to this dreaded catastrophe. These small appropriations by congressional committees reported above accelerated the whole process and have saved about one million heart attack victims "with hearts just too good to die" at a start up cost of $120 per salvage.

About 4 years ago I predicted that because of lack of funds, we would witness a vital cardiovascular slowdown in health research and I warned that in the long run this would be costly to health care needs of the nation because it would also delay achievement of a favorable preventative program against our greatest killer, arteriosclerosis.

Simply speaking, we did not provide funds in the past decade to maintain a sufficient level of research. The lack of support might have been due to the influence of the few who aired their views that the national coronary mortality had dropped, and this might have misled our health planners to believe that further research in our nation's biggest killer was not needed. Furthermore, the results of the 10-year multiple risk factor intervention trials (MR FIT), reported in September '83, did not show that control of the 3 major risk factors was sufficient to affect the coronary attack rate or longevity.

In my opinion, it now seems the majority of the decline in coronary mortality in the USA since 1968 is attributable to successful and highly available cardiac resuscitation, earlier delivery of emergency and aggressive coronary care services, increased longevity resulting from the increased numbers of coronary bypass operations performed each year, which by itself decreased the mortality, and to the increasing application of electric pacemakers and valve surgery. Most of the medical community realizes that the prevention of arteriosclerotic vascular disease still remains an unsolved mystery requiring further research to prevent the more than one million deaths per year.

I appeal to you now to realize that more appropriate funding for promising leads can help all our people reap the benefits of a longer, more rewarding life. Today we suggest the total NHLBI appropriation be increased from $622.7 million in fiscal year 1983 to $830 million in FY '84 to bring scientists back to the laboratory in order to:

1) Help create preventative programs through basic science studies that might conquer coronary and cerebral vascular disease, (an additional $125 million per year)
2) Provide intervention techniques for noninvasive emergency room treatment of heart and vascular ailments ($30 million)
3) Develop new noninvasive methodologies for measuring blood flow ($10 million)
4) Diagnose coronary disease more simply with noninvasive space age instruments ($32 million)
5) Develop new simplified, less expensive surgical emergency room "patch-em-up" techniques ($11 million)

An increased National Research Program could send the trained research workers back to their laboratories, reduce unemployment payments, and also increase the tax rolls while the dedicated scientist solves the problems of heart disease. We know that young investigators, exquisitely trained in cardiovascular research, have become discouraged that research facilities have had to close down, and they are being forced to abandon their career in basic research to which they have been dedicated. Often they are then forced to seek opportunities in other fields that do not represent such a desperate financial struggle. It appears to me that our country has almost lost a whole generation of skilled medical research scientists.

I believe there must be thousands of such investigators, presently unemployed, who have been trained to provide new methodologies which might improve the health and reduce the suffering of our nation. In the long run, the expenditures of putting them back to work in health research projects will pay the country back tremendous benefits.

Think back to 1965 and '66 when I appeared before your Congressional committees and asked for a small appropriation of $27 million a year and think of the dividends this has paid back to the world and to our nation by saving a possible one million lives. I appear before you again - and humbly suggest you reconsider the need for a more appropriate budget for the continuing war against cardiovascular disease.

APPENDIX:

NEW DYNAMIC CONCEPTS FOR THE CONTROL OF ARTERIOSCLEROTIC HEART DISEASE (Technical information continued from Pg. 7)

Molecular Biology - The ability to dissect the human genome has just begun to impact on atherosclerosis research. Last fall, two sisters were identified who were 29 and 31 years old. These young women had cholesterol deposits in their skin and tendons and had severe coronary atherosclerosis, despite low normal cholesterol levels (177 and 135 mg/dl respectively). The only abnormalities found were low levels of two seemingly unrelated apolipoproteins (the protein part of the whole protein-fat complex called a lipoprotein) - apo A-I and apo C-III. Jan Breslow and his colleagues at Harvard have since used the techniques of molecular biology to clone the genes for these two apolipoproteins and, having done so, they constructed probes (cDNA) and found that the genes for these two apolipoproteins are normally very close to one another on the chromosome. However, in these two sisters, these genes were distorted by the insertion of extragenetic material, possibly inserted by a virus.

A few laboratories (Dr. Shapiro in Illinois, Dr. Sinenski at U. of Colorado, Dr. Simone at Stanford, and Peter Edwards at UCLA) are now starting to utilize sophisticated techniques for studying the molecular mechanisms controlling the rate-limiting enzyme in cholesterol biosynthesis -HMG-CoA reductase. Drs. Brown and Goldstein and their colleagues in Dallas have just cloned the gene for this enzyme, opening up the possibility for understanding and even controlling these processes in ways never before dreamed possible.

Cell Biology - Drs. Brown and Goldstein in Dallas have discovered the way in which normal cells take up macromolecules and have shown us that an abnormality in the recognition protein (receptor) for the major cholesterol carrying lipoprotein (LDL) results in familial hypercholesterolemia and premature atherosclerosis. Drs. Gerrity (Cleveland Clinic); Schwartz (Univ. Texas, San Antonio); Fowler (Rockefeller University), and Russel Ross (U. Washington in Seattle) have demonstrated that one of the earliest abnormalities in atherosclerosis is a collection of cells that are derived from the white blood cells. These particular white blood cells (monocytes) convert into scavenger cells (macrophages) in a variety of tissues during injury and repair. However, in atherosclerosis, these cells accumulate in the artery wall and become engorged with a particular form of cholesterol — cholesteryl esters. Drs. Brown and Goldstein in Dallas, our laboratory at UCLA, Dr. Mahley and his colleagues in San Francisco, Dr. Steinberg at UC San Diego, Dr. Chait in Seattle and Dr. Soutar and her colleagues in England have found that these cells accumulate this particular form of cholesterol only when it is presented in a form that fits into the biological locks on the cell surface (recognition proeins called receptors) that are different from the normal (LDL) receptor. Thus, the major cholesterol carrying protein in the blood, LDL, may not be the culprit but some subpopulation of lipoproteins entering the cells by unregulated receptors may, in part, initiate these early abnormalities. In our laboratory at UCLA, we have found that other white blood cells (lymphocytes are capable of secreting hormones (lymphokines) that may protect the macrophage against cholesterol accumulation.

Biochemistry - The discovery of the prostaglandins has opened up new possibilities for understanding and perhaps controlling blood clotting in atherosclerosis. The balance between those prostglandins that cause clotting (thromboxane A_2) and those that prevent clotting in the artery wall (prostacyclin) may be crucial in both the development of atherosclerosis and in converting a nonobstructive blockage into a clinical catastrophe.

Dr. Mahley and his colleagues in San Francisco have applied modern biochemical techniques to the genetic analysis of a familial form of high blood fats associated with early atherosclerosis (Type III hyperbetalipoproteinemia) performed by Drs. Breslow and Zannis of Boston. The result was a demonstration of an abnormality in one of the apolipoproteins (apoE) that is somewhat analogous to the defect in sickle cell disease.

Drs. Brown and Goldstein in Dallas, Dr. Yachnin (U. Chicago), Dr. Kandutsch (Bar Harbor, Maine) and Dr. Siperstein (UC San Francisco) have shown that a product of the rate-limiting enzyme in cholesterol production that is not cholesterol itself is crucial to the cell cycle and may be important in the cell replication of atherosclerosis. Moreover, this compound(s) may be an extraordinarily potent regulator of cholesterol production.

Metabolism - Dr. John Edmond at UCLA has recently shown that ketone bodies (metabolic end products of saturated fat metabolism) may be important in cholesterol production. This exciting development promises to clarify a previously murky but important area of metabolism.

In Oregon, Dr. William Connor and his colleagues have found that the fat consumed by Eskimoes contains special fatty acids (omega three fatty acids) that actually lower cholesterol levels and prevent blood clotting.

Epidemiology - As you are aware, there is strong evidence that high density lipoproteins are inversely correlated with the risk for atherosclerosis. The molecular mechanisms for these findings are not yet known. However, Dr. John Dietchy and his colleagues in Dallas have shown that these lipoproteins bind products from bacteria that damage endothelial cells. This novel function of the high density lipoproteins may turn out to be important in protection against atherosclerosis.

Animal Models - Until now, this field has had to largely rely on cholesterol fed animal models. However, Dr. Watanabe in Japan has recently succeeded in breeding a rabbit that genetically lacks the recognition protein (receptor) for the cholesterol carrying protein, LDL. Of even more interest, this rabbit spontaneously develops atherosclerosis and dies of heart attack within 2-3 years. The location of the atherosclerosis is even remarkably similar to the location in humans. This animal model will allow us to answer many previously unanswered questions, including why the obstructions of atherosclerosis occur at one point in the artery but not at others located only a short distance away?

CONCLUSION:

These are just a few of the exciting new developments that promise to substantially increase our understanding of the atherosclerotic process. This process is complex and it affects at least half of the entire adult U.S. population. As we have said many times, the problem of atherosclerosis will not be solved by simply stopping cigarette smoking, dieting and exercising. However, the time is right for major advances that are based on the solid foundation of the scientific discoveries described above. A number of scientific disciplines are involved and this is a fundamental strength. However, this will, of course, mean supporting a variety of different kinds of scientific laboratories. The cost will be high -- millions of dollars more than is currently available -- but the investment is sound and will ultimately pay dividends that can't be measured in dollars.

Advances in Clinical Management of Acute Myocardial Infarction in the Past 25 Years

ELIOT CORDAY, MD, FACC, STEPHEN R. CORDAY, MD, FACC

Los Angeles, California

The management of acute myocardial infarction in the past 25 years has emerged from a state of masterful inactivity to one of intensive care based on a new discipline of aggressive management. This has increased the chances of survival of the victim of infarction and could well be one of the major reasons for the decline in mortality due to coronary heart disease in the United States since 1968. Because resuscitative techniques must be instituted within 4 minutes after the onset of cardiac arrest, the attendant nurse had to learn the new emergency lifesaving techniques and assume a crucial role as a physician's assistant. The various stages in the evolution of coronary care discipline began with cardiopulmonary resuscitation and were followed by pacemaker application, arrhythmia prophylaxis and insertion of pulmonary venous flow-directed catheters and arterial lines that permit monitoring and control of ventricular filling pressures. Other developments in better management of the failing heart have included methods to salvage jeopardized myocardium, strategies for the prevention of sudden death, the application of revascularization techniques after acute coronary occlusion and new noninvasive computerized technology to provide enhanced contrast images of cardiac perfusion that can be directly integrated with measurement of function.

Myocardial infarction, the nation's biggest killer 25 years ago, retains that position despite the revolutionary innovations established in 1965 for its more aggressive management (1). Before that historic date, this treacherous condition was considered the natural end result of coronary heart disease, which terminated life as though it were an unavoidable act of fate. In fact, the medical profession of 1965 could provide little in the way of specific treatment to influence the course of this disease. The standard treatment of acute myocardial infarction was bed rest, the oxygen mask and the judicious use of opiates to relieve pain. Anticoagulant therapy was adopted as standard practice to prevent mural thrombus from embolizing, but there was considerable debate about the actual benefit of this treatment because clinical study had shown that it could have harmful effects. The customary regimen of 4 to 6 weeks' bed rest was also being challenged because of an increasing belief that such inactivity caused phlebothrombosis of the peripheral circulation that could result in death from pulmonary embolization.

Comprehensive investigations in the late 1950s and early 1960s demonstrated the ominous hemodynamic consequences of arrhythmias and their ability to cause significant ischemia of the target organs, particularly of the myocardium, when they were associated with a reduction in systemic blood pressure (2–4). Therefore, administration of vasopressors was advised for supportive treatment of arrhythmias associated with hypotension and this often aborted tachyarrhythmias (5).

Cardiogenic shock, which often supervenes after coronary occlusion, was considered a serious emergency because it was accompanied by an 80 to 90% mortality rate. It was advocated that shock be treated by restoring diastolic coronary filling pressures with blood transfusions or peripheral vasoconstrictors, such as norepinephrine or metaraminol (6–8). However, some authorities feared that these agents might cause a further increase in the work load for the already failing heart (9). If ventricular fibrillation or cardiac standstill occurred during acute myocardial infarction, it was considered an untreatable terminal condition.

A New Era Emerges

Closed chest cardiac resuscitation. When electrical defibrillation proved effective for cardiac resuscitation in the operating room (10–15), this maneuver was also recommended for resuscitation of the victim of myocardial infarction. But at that time, successful defibrillation necessitated open chest massage and direct contact of the electrodes

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with the heart. By 1960 it was advocated that open chest resuscitative techniques be replaced by the simple and more practical closed chest resuscitation methods developed by Kouwenhoven et al. (12–14). "Space age" bedside electrocardiographic cathode ray monitor scopes with alarms for high and low heart rates were developed to warn the nursing staff of arrhythmias and of the onset of a cardiac arrest (11–13). Investigations on the fate of patients who had cardiac arrest in the operating rooms of Los Angeles hospitals established that if resuscitative measures were not instituted within a 4 minute time limit (15), the heart might be resuscitated, but the brain, which could not withstand such prolonged anoxia, was likely to become so severely damaged that the victim would survive only as a helpless decerebrate. It was repeatedly shown that in 60% of animals and human beings who developed cardiac arrest, the arrest occurred within the first hour after the acute myocardial infarction. Therefore, it was urged that all patients suspected of having an infarction be rushed to a facility where emergency resuscitative measures were possible (16).

The coronary care unit. By 1965, effective closed chest resuscitation and safe electrical countershock and defibrillation techniques began to be accepted by cardiologists (11–17). Although approximately 14 coronary care units had been established across the continent, most cardiologists questioned the clinical benefits of such units. Many believed that the aggressive management of coronary occlusion was an expensive exercise in futility, but a few investigators reported dramatic lifesaving results. A Bethesda Conference of coronary care unit directors convened at the American College of Cardiology headquarters in December 1965 to determine if the newly proposed aggressive management in an intensive coronary care unit could ever be of practical benefit (1). During the deliberations, participants soon realized that the coronary care directors at three centers—Hughes Day in Kansas City, Lawrence Meltzer in Philadelphia and Paul Unger in Miami—were reporting salvage of a significant number of victims of cardiac arrest. They were able to accomplish this feat because their nurses were in constant attendance in the coronary care unit and had been trained to read the abnormal heart rhythms that could document onset of cardiac arrest on the fast-moving cathode ray electrocardiographic monitor. These nurses had also been trained to perform immediate cardiac resuscitation using closed chest ventilation and electrical defibrillation (1). By allowing the attending nurses to defibrillate the patient's heart even in the absence of a physician, many patients could be saved. The Conference concluded that because of the narrow 4 minute time limit, the nursing staff must be trained to perform cardiopulmonary resuscitation and to administer appropriate prophylactic pharmacologic interventions, such as antiarrhythmic drugs, to prevent cardiac arrest. The Conference report (1) recommended that the U.S. Congress appropriate funds for training the coronary care nursing staff in their new responsibilities. By March 1966, the president of the American College of Cardiology, accompanied by the executive director, presented Senator Lister Hill with the Bethesda Conference Committee's recommendation for 3 years' funding of a nationwide training program for nurses. The senator agreed with the report and within 5 days arranged to have the necessary appropriation of $27 million attached to a railroad bill that was subsequently signed by President Lyndon Johnson. This is really a most appropriate use of the term "railroading."

Under the strong leadership of Samuel Fox III, head of the Heart Disease Control Section of the U. S. Public Health Service, training programs based on new aggressive principles for treating the victim of myocardial infarction were rapidly instituted across the nation and by 1968, some 6,000 of the larger hospitals in the country were prepared to administer immediate resuscitation and defibrillation in the newly established coronary care units. New state laws had to be instituted to permit nursing staffs to assume duties that were previously performed only by physicians. Soon other aggressive programs, including the judicious use of pacemakers and antiarrhythmic drugs, were adopted to prevent further complications from arrhythmias that might otherwise herald the onset of cardiac arrest (18).

Benefits derived from coronary care units. The coronary care programs of the American College of Cardiology and the American Heart Association were accepted with unanticipated vigor because of widespread publicity that the lives of thousands of people with a heart "too good to die" were being saved. Within a few years, most states had passed laws requiring practitioners to pass a cardiopulmonary resuscitation examination before they could renew their annual staff privileges. The conferees of the Bethesda Conference estimated that 45,000 lives per year would be saved with the adoption of the new aggressive methods in the coronary care unit (1). However, the health planners did not set up randomized studies to learn exactly how many lives could be saved by the coronary care units. In recent years, some attempts to determine the survival rates have yielded statistics that seem to refute any possible benefits derived from the coronary care unit concept. However, these efforts have been discounted by some because the numbers were too small and the subgroups were not appropriately organized to provide statistically meaningful results. The cardiac care units in the studies were considered substandard in organization and quality, and many patients were transferred in and out of the coronary care unit because their risk of death changed after initial randomization. It now seems to be too late to perform an appropriate randomized study because there is such great faith in the coronary care unit and the aggressive management entailed has become standard practice. To those who doubt the efficacy of the coronary care unit, we suggest they review the survival statistics of the thousands who were resuscitated in their local facilities to see that without such resuscitative maneuvers, survival of victims of cardiac arrest would be rare.

A More Appropriate Research Program Initiated to Improve Basic Knowledge About Acute Myocardial Infarction

Stimulated by these dramatic breakthroughs, Robert Grant, Director of the National Heart Institute, noted that the research budget for myocardial infarction, the nation's leading cause of death, received only a meager 1% of the total research allotment made by the National Institutes of Health. After raising a congressional appropriation of about $15 million a year, with the help of Michael DeBakey, to support more intensive studies in basic research and clinical applications for the management of acute myocardial infarction, Grant died suddenly, the victim of a fatal heart attack. But the momentum created by his endeavor has continued to this day and made many other dramatic breakthroughs possible.

Myocardial infarction research units. The program eventually blossomed into nine productive myocardial infarction research units across the nation, under the direction of Peter Frommer, MD, of the National Heart Institute. Many new clinical concepts emanated from these myocardial infarction research units. One of the most important advances attributed to the program was the development of the Swan-Ganz pulmonary artery flotation catheter, which enables continuous hemodynamic monitoring of cardiac output and regulation of fluids and drugs to provide most appropriate left ventricular filling pressures (18). Intraarterial pressure lines were adapted to monitor systemic vascular resistance for better regulation of coronary filling pressures and the afterload of the failing heart by application of vasodilators, vasopressors or alpha- or beta-receptor blocking agents, or both. This ingenious online monitoring of hemodynamic function has saved many patients with complications of pump failure (18,19). The hemodynamic monitoring, now a standard form of therapy, was an effective aid in the management of interventions such as volume loading, intraaortic balloon assistance, afterload and preload reductions or administration of selective vasopressors. Thus, the occurrence of, and mortality from, cardiogenic shock is now markedly diminished (19).

Preservation of Jeopardized Ischemic Myocardium

Pharmacologic interventions. Starting in 1968, interest was renewed in methods that might preserve jeopardized ischemic myocardium (6,20,21). It was thought that such preservation would reduce infarct size and prevent subsequent chronic cardiac decompensation, troublesome arrhythmias and sudden death. Some pharmaceutical agents proposed for salvaging jeopardized myocardium were nitroglycerin, nitroprusside, hypertonic mannitol, propranolol hydrochloride, hyaluronidase, prednisolone, allopurinal and heparin. Although these investigations stimulated great interest, by 1976 the published data consisted of many conflicting claims and the status of the concept of myocardial salvage had to be reevaluated (21–24). Actually, each of the opinions seemed to be correct for the investigator's particular protocol design, but the contradictory results seemed to emanate from the differences in study models (dogs versus human beings) and in the mode and schedules of administration of the pharmaceutical agent or physical interventions. It appeared that the mode of administration and timing of an intervention must be uniform. In retrospect it appears that if more than 3 hours elapsed between the onset of the coronary occlusion and the intervention, the ischemic myocardium would have been so irreversibly damaged that any treatment stood little chance of salvaging significant amounts of myocardium (22–24).

Reperfusion phenomenon. In addition, some investigators revealed an unusual phenomenon that occurred in about 16% of animals undergoing reperfusion within 4 hours of occlusion (24). This phenomenon was associated with serious arrhythmias and a metabolic disturbance of the myocardium that included loss of potassium and anaerobic lactic acid production. At necropsy, the myocardium was characterized by hemorrhage, interstitial and intracellular edema of the ischemic area and fragmentation of the myofibrils. It was believed that such swelling in the ischemic area prevented blood from reentering the region, causing a "no reflow" phenomenon (24). It is evident that the earlier the reperfusion is started—by coronary bypass surgery, thrombolysis, synchronized retroperfusion or other general supportive hemodynamic measures (such as reduction in afterload or improved preload)—the better the possibility of preventing the reperfusion phenomenon (19).

Sudden Cardiac Death

New concepts have emerged since 1966 concerning sudden cardiac death, a syndrome that claims between 300,000 to 400,000 lives each year in the United States (25–29). Abnormal rhythms and atrioventricular conduction defects that might warn patients that they are in danger include high grade premature ventricular beats, ventricular tachyarrhythmias or bradycardias due to ischemic heart disease. Unfortunately, because of their ischemic origin, these arrhythmias are resistant to prophylactic therapy. The risk factors associated with sudden cardiac death appear to be those that indicate already well established coronary disease and include previous myocardial infarction, abnormal electrocardiograms or ventricular arrhythmias, but not the usual risk factors of arteriosclerosis as we now understand them (18, 19,25–29). There is a high risk of sudden cardiac death in patients who have sustained a myocardial infarction during the previous year, and particularly in those who have evidence of significant ectopic arrhythmias in the 2nd and 3rd weeks after acute myocardial infarction. Our main thrust must be to provide practical techniques to identify the candidate for sudden cardiac death and to provide more effective prophylactic agents that might prevent the catastrophe (19).

New Diagnostic Technology of Acute and Chronic Ischemic Process

In the past decade, the limits of accuracy of both new and established techniques to diagnose the acute and chronic ischemic process, including electrocardiographic stress tests, angiography and enzymology, have been placed in their proper perspective (19). For instance, selective coronary angiography and ventriculography have been improved in the past 25 years to localize and measure the degree of obstruction within the native coronary circulation as well as abnormal ventricular wall motion, chamber volume and ejection fraction associated with myocardial ischemia (19). But diagnostic decisions must be based on the assessed degree of coronary artery narrowing, and these assessments are not clear cut and are often subject to large margins of error in quantitation (19). Cost-effective technology must be developed to improve the angiographic technique to provide even better images for quantitative measurements with less radiation and less financial expense to permit safer, more economic and more certain selection of the candidate for coronary bypass surgery, percutaneous coronary angioplasty or thrombolysis. Many clinicians recommend early coronary angiography for patients surviving myocardial infarction, but most believe that this expensive process should be reserved for patients with continuing symptoms.

New Image Technology

Recent advances have been made in imaging pathophysiologic phenomena of the beating heart with nuclear scintigraphy, two-dimensional echocardiography and digital subtraction angiography. Each of these techniques can portray normal or abnormal cardiac function, such as wall motion abnormalities that change from a normal inward contractile motion toward the center of the left ventricle to a loss of such contractility (akinesia) or ballooning outward (dyskinesia). They also can portray ventricular wall thickening during systole and reveal thinning of the wall in ischemic situations. Chamber volumes in diastole can be seen to increase within a few heartbeats after coronary occlusion, and ejection fraction diminishes. In addition, the nuclear tracer thallium will accumulate in normally perfused regions and its absence can be utilized to portray a region of ischemia or infarction.

Radionuclide technology. Although attempts had been made to apply radioisotopic methods to cardiology since 1947 (6,30–36), advances in this technology were not possible until improved scintigraphic techniques were developed to image the low concentration of nuclear material passing through the cardiac chambers or deposited in the myocardium. Computer applications and background subtraction in the last decade made significant image enhancement possible (36). Nuclear methods can now be applied for the management of patients with myocardial infarction to image the extent of an acute or chronic ischemic process, detect transient ischemic events after stress and correlate these findings with measurements of regional wall motion abnormalities, cardiac volume and ejection fraction.

Two-dimensional echocardiography. In the past 6 years, two-dimensional echocardiographic techniques were developed to quantitate alterations in cardiac function (37–40). Alterations of cardiac function ascribed to ischemia include regional and global alterations in chamber volume, wall motion and wall thickening. Most often these changes occur within the first few heartbeats after coronary occlusion. On early reperfusion all functional changes may be reversed. As the ischemic areas extend, further impairment of function occurs. Measurements of function with two-dimensional echocardiography that portray ischemia include those of regional wall kinetics (akinesia to dyskinesia), reduced fractional area of change, increase in right and left ventricular and atrial chamber areas and volumes, normal wall thickening that occurs during systole and changes toward thinning, ventricular aneurysm formation and papillary muscle dysfunction with prolapse of the mitral or tricuspid valve. Excellent images can now provide complete delineation of endocardial and epicardial borders for quantitating ejection fraction indexes, regional areas of change and chamber volumes. Computerization of cardiac endocardial and epicardial outlines and applied two-dimensional echocardiographic studies now provide data for evaluating changing quantitative measurements of ischemic dysfunction and physical and pharmaceutical interventions (38,39). Selected portions of the fast-moving phasic echocardiographic images processed by the computer can now be displayed side by side for serial comparison and quantitated automatically by the computer to depict the degree of progressive ischemic dysfunction or the benefits of interventions during the management of the patient in the coronary care unit (37). Contrast injection techniques developed by our group (41) permit identification of regions of ischemia for more accurate diagnosis of developing anatomic lesions or reperfusion phenomena. Further, two-dimensional echocardiographic bicycle stress tests have been perfected to provide diagnostic images of abnormal ischemic wall motion and changes in chamber volume while the patient is exercising (40).

It is now evident that the clinician can confidently choose from a battery of electrocardiographic, ultrasonic and nuclear methods that complement and supplement the knowledge of a single test to detect the earliest abnormalities of ischemic dysfunction when a myocardial infarction occurs (32–42).

Unsolved Problems of Acute Myocardial Infarction

Existing controversies continue regarding fundamental concepts in causation of acute ischemia leading to infarction (19). Some workers believe that most cases of infarction result from coronary angiospasm, but others observe that this is a rare occurrence (43). Dynamic pathophysiologic concepts must explain when the irreversible ischemic changes occur. Are clinical infarct size measurements accurate? Is there an ischemic "twilight zone" around a central area of necrosis that can be reversed by delayed interventions? What is the significance of the collateral circulation in control of infarct size and how can it be implemented? Emerging concepts that are associated with ischemic syndromes must receive more attention, such as the excessive metabolic demands in hypertrophic cardiomyopathies and the relation of acute myocardial ischemia to the prolapsing mitral valve syndrome. The attending cardiologist needs to know if it is possible to reduce the obstructive arteriosclerotic lesion by control of risk factors after myocardial infarction occurs (19). However, there is considerable disagreement regarding the possible benefits of risk factor interventions to prevent atherosclerosis (44,45).

Revascularization of the Acute Ischemic Myocardium

New developments in the attempt to revascularize ischemic myocardium immediately after coronary occlusion are of great interest to the cardiologist (46,47). These interventions include: 1) immediate coronary bypass; 2) systemic intravenous administration, intravenous coronary sinus retroperfusion and antegrade coronary artery flushing of streptokinase to dissolve an occlusive thrombus (44,45); 3) percutaneous transluminal coronary angioplasty (PTCA) of a narrowed coronary artery (48); and 4) the use of synchronized retroperfusion of arterial blood that is cooled below body temperature and pumped into the heart by way of the coronary sinus (47). The latter two interventions are of great interest but must still be considered to be of an experimental nature. It is obvious from previous studies that these interventions must be applied as early as possible, at least within 3 to 4 hours after occlusion, before the heart damage becomes irreversible. These experimental methods will be discussed in more detail in early issues of this Journal (49).

Conclusions

Stages of New Aggressive Interventions for the Management of Acute Myocardial Infarction

The stages of the rapid developments in the modern management of myocardial infarction can be summarized chronologically:

Stage 1. Continuous electrocardiographic monitoring of the acute coronary patient

Stage 2. Authorization and training of attending nurses to defibrillate the heart of patients

Stage 3. Prophylactic and continuous intravenous drip treatment of the irritable heart

Stage 4. Electrical pacemakers for treatment of acute heart block and extreme bradycardia

Stage 5. Pulmonary artery flow-directed catheters for estimating left ventricular filling pressure

Stage 6. Treatment of the failing heart by control measures affecting afterload and preload

Stage 7. Interventions to salvage jeopardized ischemic myocardium, including revascularization with thrombolytic agents and coronary sinus retroperfusion

Stage 8. Coronary bypass surgery for: a) acute coronary occlusion, b) impending infarction, c) high risk lesions, d) extending infarction

Stage 9. New noninvasive imaging technology

Why the Reduction in Coronary Disease Mortality?

Many wonder about the probable reasons for the decreased mortality of coronary heart disease since 1966 despite an unchanged incidence of acute myocardial infarction (50). Many factors appear to be responsible: 1) public awareness of the acute coronary symptoms and the need to seek emergency skilled treatment; 2) practical resuscitation within the 4 minute limit for emergency treatment of cardiac arrest; 3) aggressive management of the acute coronary victim in the coronary care unit; 4) prophylactic treatment of ominous arrhythmias; 5) aggressive management of pacemaker problems; 6) acceptance of beta-receptor blocking agents and nitrates for treatment of angina pectoris; 7) coronary bypass surgery for up to 150,000 potential victims of coronary disease in the United States each year; 8) freedom from catastrophic epidemics of influenza in recent years which has improved longevity of all patients; 9) alterations in the International Classification of Diseases, which changed statistical methods for providing death classification each year; and 10) control of risk factors such as hypertension, tobacco smoking (43) and perhaps even serum lipids.

At present each cardiologist has his or her own private beliefs on how the battle is being won, and we must await the renewed scientific analysis to determine which of the advances has contributed most to the reduced mortality.

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STATEMENT OF DR. JAMES W. PRESCOTT, PRESIDENT, BIOBEHAVIORAL SYSTEMS

Senator PROXMIRE. Now we'll move to the National Institute of Child Health and Human Development.

And Dr. James Prescott, president of Biobehavioral Systems is with us.

Dr. PRESCOTT. Thank you, Mr. Chairman. I appreciate the opportunity of testifying before your committee.

As a matter of introduction, I'd like to indicate that currently I am president of the Biobehavioral Systems. Prior to that I was health science administrator with the developmental behavioral biology program of the National Institute of Child Health and Human Development for 14 years; prior to that, Assistant Head of the Physiological Psychology Branch, Office of Naval Research.

My testimony today is to bring to your attention an inexplicable administrative action of Dr. Norman Kretchmer, the former Director of NICHD, who abolished that agency's responsibility to support basic research on "child abuse and neglect" and "developmental origins of violence."

For 14 years, we have been studying the nature of these problems, and we have made a number of significant breakthroughs, demonstrating that, indeed, abuse and neglect lead to impaired brain development and a variety of abnormal emotional behaviors, including extreme uncontrolled violence as juveniles and adults.

We were in the process of demonstrating, based upon research findings, abnormal subcortical spike discharge activity in the brains of animals who were reared under conditions of deprivation of this kind.

And we're in the process of extending this to screening of criminals who have a history of violence and impaired brain function. The success of such a diagnostic technique, of course, will result in the saving of many lives—infants, children, and women particularly.

And it was that line of research that Dr. Kretchmer objected to, and it ultimately resulted in the abolition of the agency's responsibility to continue research in this area.

I cited in my written testimony the Public Law 87–838 passed by the Congress, which requires the Institute to support research and training in the special health problems of mothers and children, of which, clearly, child abuse and neglect would be interpreted as a special health problem. Obviously, it includes the fathers and other caretakers as well.

The intent of this testimony is to request this committee and the Congress to redirect the NICHD's agency responsibility to complying with Public Law 87–838 and to continue its support for understanding the causes and long-term consequences of child abuse and neglect, which are devastating to the future of children and to our society.

I don't think I need to burden, at this time, the committee with all the statistics that document the violence against infants and children, which is significantly greater than the violence in the general population, aside from the statistics in the report.

I would also like to, of course, point out, in a recent report in the Washington Post by Mary Thornton, coming from the Office of Juvenile Justice, that some 5,000 to 8,000 bodies of unidentified children are found each year.

The magnitude of the problem is enormous, Mr. Chairman, and we do not have really good statistics on what's really happening to our infants and children.

And the consequences, again, are widespread. There are intellectual deficits of functional mental retardation, emotional disturbances. And the crime, the violence, the alcohol and drug abuse are all outcomes of this kind of abusive, neglecting environments.

And I can't emphasize too strongly that, in my view, the issues of child abuse and neglect and violence in general in our society are the most important public health problems in this Nation.

And Surgeon General Koop, in a recent address on violence and public health, made the same statement.

And so, hopefully, this Congress and this committee will take the appropriate action to restore the responsibility to NICHD to support research in this area.

I might point out there is no Federal agency today that has any systematic program of research of understanding the effects of abuse, neglect, and impoverished environments upon brain development and behavior.

And this simply, in my view, cannot be of greater national priority.

And I thank you for the opportunity to express these views to you, and I'll be willing to answer any questions.

Senator PROXMIRE. Well, thank you, Dr. Prescott, very much for your fine statement.

[The statement follows:]

STATEMENT OF DR. JAMES W. PRESCOTT

Mr. Chairman, I am a developmental neuropsychologist and a cross-cultural psychologist. I received my Ph.D. from McGill University, Montreal, P.Q. Canada in Psychology and have been in public service for most of my professional career. First, as Assistant Head, Physiological Psychology Branch, Office of Naval Research, Department of Navy (1963-1966); and secondly, as Health Scientist Administrator, Developmental Behavioral Biology Program, National Institute of Child Health and Human Development (NICHD),NIH (1966-1980).

My testimony today is to bring to your attention an inexplicable administrative action of Dr. Norman Kretchmer, former Director, NICHD,NIH which abolished that agency's responsibility to support basic research on "child abuse and neglect" and "developmental origins of violence"; and to request Congressional review and reversal of that unexplained administrative action which violated PL 87-838, Sec. 441, October 17, 1962. This Act of the Congress established the NICHD and contained the following charge to the NICHD:

> "...to establish in the Public Health Service an institute for the conduct and support of research and training relating to maternal health, child health, and human development, including research and training in the special health problems and requirements of mothers and children..." (italics mine).

By any common understanding of the English language, "child abuse and neglect" constitutes " a special health problem...of mothers and children." (By this Congressional language I do not imply that fathers are not equally responsible for "child abuse and neglect.").

This unilateral action taken by Dr. Kretchmer was also in violation of Sec. 443(a), PL 87-838 which established "an advisory council to advise, consult with, and make recommendation..." Dr. Kretchmer failed to comply with this provision of Public Law by not consulting with the NICHD National Advisory Council on a major research policy change for the NICHD. Further, Dr. Kretchmer violated PL 89-487, July 4, 1966 which states:

> "...every agency shall separately state and currently publish in the Federal Register, for the guidance of the public--(b) Agency Opinions and Orders--(B) those statements of policy and interpretations which have been adopted by the agency and are not published in the Federal Register, and (C) administrative staff manuals and instructions to staff that affect any member of the public..."

Dr. Kretchmer failed to comply with PL 89-487 and otherwise failed to inform the public and the Congress of a major change in agency research policy.

It is a matter of NICHD history that the NICHD published a document entitled: Perspectives on Human Deprivation: Biological, Psychological and Sociological (1968) which outlined the future scientific programs and directions of the NICHD on this subject matter of "developmental origins of violence". Chapter IV: Biological Substrates of Development and Behavior specifically identified "maternal-social deprivation" as a significant etiological factor in parental violence against their offspring and which required further intensive study. This finding and recommendation was further reinforced in Chapter V: Towards A Research Policy For Psychosocial Deprivation where it stated:

> "Preliminary data suggest that there are organic deficits in the brain and nervous system associated with early maternal-social deprivation and thus suggests a biological basis and predisposition to violent-aggressive behavior".(p. 294).

The National Advisory Child Health and Human Development Council in its November 1968 meeting fully endorsed that publication and passed the following resolution:

> THE NATIONAL ADVISORY CHILD HEALTH AND HUMAN DEVELOPMENT COUNCIL RESOLVES THAT THE NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT, IN RESPONSE BOTH TO ITS MANDATE AND TO THE COMPELLING NATURE OF THE HUMAN PROBLEMS OF OUR TIMES, STRONGLY SUPPORT AN EXPANDED PROGRAM OF RESEARCH AND TRAINING IN THE BIOMEDICAL AND PSYCHOSOCIAL ASPECTS OF HUMAN DEPRIVATION.
>
> THE NATIONAL ADVISORY CHILD HEALTH AND HUMAN DEVELOPMENT COUNCIL FURTHER STRONGLY URGES THAT THE NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT BE GRANTED ALL NECESSARY RESOURCES TO ACCOMPLISH A MAJOR RESEARCH AND TRAINING EFFORT IN THE BIOMEDICAL AND PSYCHOSOCIAL ASPECTS OF DEPRIVATION, INCLUDING FUNDS AND APPROPRIATE STAFF POSITIONS. RECOGNIZING THE UNUSUAL COMBINATION OF FIELD AND LABORATORY RESEARCH PROGRAMS REQUIRED--INCLUDING THE ESTABLISHMENT OF EXPERIMENTAL FIELD STATIONS--THE COUNCIL RECOMMENDS THAT FUNDING MECHANISMS AND PROJECT REVIEW ARRANGEMENTS ALLOW FOR MAXIMUM FLEXIBILITY TO ACHIEVE THESE URGENTLY NEEDED GOALS.

A copy of that book: Perspectives On Human Deprivation, now out of print, is included as an Appendix to my testimony and is submitted for your review.

Continuing this history of the NICHD and its accepted mandate to study the developmental, particularly the familial origins of violence, the NICHD included the following language "child abuse and the unwanted child" in the Division of Research Grants (DRG), NIH 1970 version of its Referral Guidelines which provides the bases for the DRG's assignment of grant applications to the respective NIH Institutes for Council review and funding. Additionally, former Secretary Caspar Weinberger, DHEW directed the NICHD in 1973 to target funding for child abuse and neglect research. Part of the NICHD response to this directive was to organize and convene the "NICHD Conference on Child Abuse and Neglect: Issues In Developmental Research" which was held on June 17-18, 1974 at the NIH. Dr. Gilbert L. Woodside, Acting Director, NICHD made the following opening remarks:

> It is a pleasure to have the opportunity to make the opening remarks at this Conference on research in the important area of child abuse and child neglect. The convening of this Conference is one of the tasks assumed by the National Institute of Child Health and Human Development in connection with the request, about a year ago by Secretary Weinberger, for increased emphasis on child abuse and child neglect by the agencies of the Department of Health, Education and Welfare.

In the July 1974 NIH Record, a short summary review of the conference was published with the concluding statement: "Conference proceedings will be published."

Dr. Norman Kretchmer assumed the position of Director, NICHD in September 1974 and on April 15, 1975, in a memo to John Burckhardt, Office of Assistant Secretary for Health, from Dr. Joseph M. Bobbitt, NICHD informed him of Dr. Kretchmer's decision that "The Institute has decided not to support the publication of the proceedings of its conference on research aspects of child abuse and neglect...". Dr. Kretchmer's action subverted the NICHD's compliance with Secretary Weinberger's directive to the NICHD and no explanation was given for this unilateral administrative action which also indicated Dr. Kretchmer's antipathy to the subject matter of "child abuse and neglect" from the earliest days of his administration.

Other items of historical relevance are noted below,as background information for the recommendations that I will submit to this Committee.

1. In April 1975, I published an article "Body Pleasure And The Origins Of Violence" in The Futurist which summarized findings from several NICHD supported research programs and my own cross-cultural studies of child-rearing practices that promote either peaceful or violent cultures. This personal research was supported by the NICHD. A companion article by Dr. Gary Mitchell entitled: "What Monkeys Can Tell Us About Human Violence" was also published in the same issue of The Futurist and summarized some of his research supported under NICHD grant HD 04335. These two articles were reprinted by the NICHD and a copy of this DHEW-NIH reprint is enclosed as Appendix B for your review. article has been reprinted in The Bulletin Of The Atomic Scientists (November 1975); in Adventures In Anthropology by Dr. William J. Kennedy; and in several other scientific and professional publications.

2. In 1976, the Board on Maternal, Child, and Family Health Research, Committee on Maternal and Child Health Research, Division of Medical Sciences, National Research Council, National Academy of Sciences submitted a 108 page report entitled "Maternal and Child Health Research" in response to a request for such a study by Dr. Kretchmer which was funded under NICHD Contract No. N01-HD-5-2818. That report observed among its many cogent observations that:

> Suprisingly, homicide ranks fifth as a cause of death for both age groups (1-4; 5-14). The rate of homicide of children 1-4 years old is twice that of older children (emphasis theirs). These facts on accidents and homicides emphasize the need for behavioral research on children's parents and surrogate caretakers. (p.5). (Year 1970).

This distinguished Committeefurther concluded in its Introduction, the following:

> Another tragic indication of poor quality of life is violence--homicide ranks fifth, and suicide ranks ninth as a cause of death in children 5-14 years old (Table II). These figures on mental retardation, emotional disturbance, neglect, abuse, poverty, and violence indicate that, to complement biomedical research, there is a need for remedial activities for those who are victims of mental handicaps and psychosocial maladies in our society. (p.11). (Year 1970).

Since 1970, Quality of Life has deteriorated even more for our children in ages 5-14 years: For this age group in 1979, homicide is now the fourth leading cause of death and suicide is the seventh leading cause of death.

LIFE IN AMERICA IS DRIVING MORE OF OUR YOUTH TO HOMICIDE AND SUICIDE!

The Committee's: Conclusions and Recommendations stated:

> Studies of social development (prosocial behavior, interpersonal competence, aggression, and attachment) are needed to balance the current emphasis on cognitive development (emphasis mine).(p.106).
>
> The NICHD should be designated the "lead agency" ("lead agency" is defined as assuming initiative and responsibility as well as a significant share of support) of the DHEW for all aspects of human development. It should conduct periodic reviews of the status of knowledge and research in this area. High priority should be given in its own intramural and extramural research for support on vanguard and underactive parts of the field. (p. 107, emphasis mine).

3. In a report dated February 1977 and entitled: Federal Research Activity In Mental Retardation: A Review With Recommendations For The Future, submitted by the Ad Hoc Consultants On Mental Retardation to the Directors, NICHD and NIMH, stated the following:

> Although the Office of Child Development has the legislative responsibility for child abuse, it needs the help of NICHD and NIMH to elucidate underlying causes. Without such knowledge, lasting solutions will be impossible (p. 65, emphasis mine).

4. In the January 1978 Report To The National Advisory Child Health and Human Development Council by the Human Learning and Behavior Branch, NICHD, I summarized the NICHD's past, present and future research efforts on the origins of violence and the need to pursue evidence of brain dysfunction and damage consequent to child abuse and neglect which appeared responsible for many uncontrolled acts of adult violence. Specific mention was given to developing a neuropsychological diagnostic method to detect "subcortical spike discharges" from deep brain structures in those individuals characterized by uncontrolled violence (pp. 11; 14-15). Dr. Kretchmer approved this report and it was published as an official NICHD report. A copy of this complete report is included as Appendix C to my testimony and is provided for your review.

5. On November 6, 1978, I received an invitation from Dr. Robert Powitzky, Administrator, Psychology Services, Federal Bureau of Prisons, Dept. of Justice to give a scientific briefing at their Medical Facility, Springfield, MO. on the advances of developmental research related to violence and to pursue ways and means of exploring a feasability study to identify sub-cortical spike activity in violent offenders which required EEG recordings on magnetic tape. Dr. Kretchmer refused to approve this activity on official duty time and I gave the scientific briefing on my personal time. Upon my return, I was informed that Dr. Kretchmer disapproved my conducting this briefing on my own personal time.

6. On November 29, 1978, I received an invitation from Norman A. Carlson, Director, Federal Bureau of Prisons,to give the same scientific briefing to him and his staff. Dr. Kretchmer's administrative actions prevented the presentation of this scientific briefing.

7. On December 13, 1978, I filed an official misconduct charge against Dr. Norman Kretchmer, namely, OBSTRUCTION OF SCIENCE AND THE NATIONAL HEALTH INTEREST with the Secretary, DHEW requesting a review of NICHD research policy. This was followed by further charges of Contracts Maladministration and Financial Misconduct against Dr. Norman Kretchmer.

8. On April 3, 1979, I met with Dr. Thomas Malone, Deputy Director, NIH to discuss my charges against Dr. Kretchmer. It was agreed that Dr. Malone would establish a Health Research Policy Review Committee that would review the history of NICHD's research support of Psychosocial Deprivation and Dr. Kretchmer's decision to abolish NICHD's agency responsibility to continue its mission responsibility to support research on the Developmental Origins of Violence. Dr. Malone failed to establish such a review committee.

9. On May 16, 1979, in a memorandum to Dr. Malone which expressed my concern that he had taken no action to establish a Health Research Policy Review Committee per our agreement of April 3, 1979, I requested that the matter be forwarded to the Secretary, DHEW for Departmental review. Dr. Malone refused to comply with this request.

10. In the Summer of 1979, I wrote about two dozen official letters to various scientists and pediatricians apprizing them of Dr. Kretchmer's actions and expressed my concern about the increasing violence in our society and the lack of

knowledge base to prevent such violence, particularly against infants & children.

11. On April 11, 1980, I was dismissed from a 17 year federal career in science administration for the following reasons:

> Removal for improper use of official position and resources to promote research on 'developmental origins of violence' and'child abuse and neglect', subjects that are not within the mission of the NICHD, as part of the programs of this Institute.

The Merit System Protection Board sustained Management's action of dismissal because of "employee...actions (that) impedes the agency's ability to carry out it's mission"; and to "promote the efficiency of the service."

Additional history could be provided but limitations of time and space prevent a summary of all those events that led Dr. Kretchmer to abolish NICHD's agency responsibility to support basic research on "child abuse and neglect" and "developmental origins of violence." It is emphasized, however, that Dr. Kretchmer in an interview with William E. Howard, Editor and Publisher, Child Protection Report, stated in the September 6, 1979 issue that:

> We were never in child abuse or domestic violence research. Our work is in the area of child development. We don't do any pathology--that's the mission of the National Institute of Mental Health.

Two of those statements are factually incorrect since the NICHD has and continues today to support research on child abuse and neglect; and approximatley 40% of the NICHD programs of research involve "pathology".

Dr. Kretchmer's factually incorrect statement was conveyed to Secretary Schweiker and used in his response of May 11, 1981 to Senator Charles Mc C. Mathias's inquiry of February 23, 1981 concerning the role of child abuse and neglect research at the NICHD. Secretary Schweiker stated that: "The NICHD has never supported a program of research on child abuse and neglect". This same identical statement was made by Dr. James B. Wyngaarden, Director, NIH in a letter of October 5, 1982 to Congressman Henry A. Waxman.

The seriousness of this deliberate misrepresentation of material fact to the Congress adds to the gravity of the NICHD/NIH's abandoning the cause of abused and neglected children and those infants and children who are victims of homicidal assault---and for what reason? It is a matter of record that the NICHD is currently supporting child abuse and neglect research with Dr. John Money, The Johns Hopkins University School of Medicine (HD 00325); and that previously of Drs. Powell and Blizzard, Department of Pediatrics, The Johns Hopkins University School of Medicine (HD 01852); and that of Dr. Ingeborg Krieger, Childrens Hospital of Michigan (HD 01104). Other examples could be cited.

All of the above NICHD grants studied the "Failure To Thrive Syndrome" and the "breakthroughs" that identified child abuse and neglect as the primary etiological factor in the "Failure To Thrive Syndrome" or "Psychosocial Dwarfism" came from NICHD supported research at The Johns Hopkins University School of Medicine.

The importance of child abuse and neglect for the future of our children and our society cannot be overestimated. It is a major precursor to juvenile and adult crime and violence (assaults, homicide & suicide); depression; arrested mental development; infant and child "accidental" deaths; , alcohol and drug abuse; and is a hidden variable in our infant/child mortality rates where the increase in infant/child homicide rates is significantly greater than the increase in homicides for the general population. For example, from 1950-1976, the murder rate has increased:

70% for the general population

325% for white male children ages 1-4 years

544% for non-white male children ages 1-4 years

We are killing these children at an increasing rate that is 6.2 times greater than for the general population. Why?

It is for good reason that Surgeon General C. Everett Koop, M.D. stated in his address on Violence and Public Health (October 26, 1982) that:

> Violence...is one of the most extensive and chronic epidemics in the public health of this country"...This is a call to action on your part--individually and collectively--to address this issue of violence by discussion, study and research." and
>
> First, there seems to be no other institutional focus for research into the causes of violence that takes into account the multiple biological, psychological, social, and societal dimensions of crime, its victims, and its prevention. The institutions closest to being able to provide a multidisciplinary approach to research in the prevention of family violence, for example, would be the National Institute of Mental Health and the National Institute of Child Health and Human Development (p.10).

This evaluation was exactly the evaluation made in 1968 in the NICHD document, Perspectives On Human Deprivation which called for the same multidisciplinary effort by the NICHD that the Surgeon General called for in 1982.

From my perspective and [illegible] data available to me there is currently no federal agency supporting a major systematic research effort on the causes and long-term consequences of child abuse and neglect, particularly upon brain development and function which is the neurobiological foundation for our intellectual, cognitive, emotional and social development. Dr. Kretchmer's action and that of NIH officials have deprived us of this vital information and has blocked further scientific advances in the development of neuropsychological diagnostic tests of impaired brain function in children who are abused and neglected; and in adults who are pathologically violent. The ability to identify the truly dangerous violent offender (impaired brain function) from the less dangerous violent offender (absence of brain dysfunction) would translate into the savings of human lifes by preventing the premature release of such violent individuals back to the community and provide a criteria for the efficacy of therapy.

The seriousness of these issues for the future of our children and that of our nation is so grave that it calls for Congressional Hearings on why the NICHD-NIH should abandon its agency responsibilities in this subject matter. This is particularly relevant given the testimony of many distinguished scientists and citizens on the establishment of the NICHD and their expectations for the NICHD. Unfortunately, time and space does not permit even the sparsest summary of that testimony.

IN CONCLUSION, the following recommendations are submitted to your Committee for Congressional action:

1. Instruct the NICHD-NIH to implement its Congressionally mandated activity under PL 87-838 to support research on the special health problems of mothers and children which includes by definition child abuse and neglect; and
2. Provide a line-item budget of $10,000,000 foraccelerated research on the biological, psychological and sociological causes and consequences of familial violence and neglect as a specific Congressional charge to the NICHD.

I am grateful for the opportunity that you have given me to present these issues before your Committee and the Congress and my views on the need for a major reorganization of the Federal Health Agencies is contained in a separate statement.

[From Psychology Today, December 1979]

THE BRAIN: ALIENATION OF AFFECTION

(by James W. Prescott)

Deprived of their mothers, Harry Harlow's monkeys were at times apathetic, at times hyperactive, and given to outbursts of violence. Raised in isolation, they were socially inept; they often held themselves and rocked like autistic children.

What Harlow could not know at the time of his dramatic experiments in the late 1950s and 1960s was that these behavioral disturbances were accompanied by brain damage. More recent studies suggest that during formative periods of brain growth, certain kinds of sensory deprivation—such as lack of touching and rocking by the mother—result in incomplete or damaged development of the neuronal systems that control affection (for instance, a loss of the nerve-cell branches called dendrites). Since the same systems influence brain centers associated with violence, in a mutually inhibiting mechanism, the deprived infant may have difficulty controlling violent impulses as an adult.

If confirmed, these studies may have profound implications for human cultures that raise their infants with low levels of touching and movement. Children in these societies may be unable to experience certain kinds of pleasure—and be predisposed to apathy and violence.

The disturbance, I believe, has its origins in the somatosensory system of the cerebellum, which regulates the sense of movement and balance (vestibular system) and the sense of touch (somesthetic system). More than other senses, such as vision and hearing, touch and movement seem directly tied to emotions like affection. And this portion of the brain is one of those most susceptible to "shaping"—changes in neuronal structure—during a child's development. In numerous studies, laboratory animals deprived of tactile and movement stimulation have exhibited abnormal social and emotional behavior.

Harlow had explained his monkeys' behavior as caused simply by social isolation and not deprivation in specific sensory, neurobiological processes. I began to suspect that the vestibular-cerebellar system was involved after a study by psychologists William Mason and Gershon Berkson, who reported that when a cloth-covered "surrogate mother" swung an infant monkey, the maternal-deprivation syndrome did not develop. To study that possibility, Robert Heath and Bernard Saltzburg at the Tulane University Medical School took electrophysiological recordings, by means of implanted electrodes, from the limbic and cerebellar regions of extremely violent, isolation-reared monkeys provided by Harlow. The bioelectrical signals from these electrodes displayed abnormal "spike" discharges, which were not seen in normal monkeys. The presence of the spikes was also detected by a unique computer analysis of scalp EEG recordings from the same monkeys' limbic and cerebellar regions.

Further evidence of the cerebellum's role was provided in a study I did with A. J. Berman and Doreen Berman of the Bronx Veterans Administration Hospital in New York. Using two of Harlow's violent monkeys, the Bermans surgically removed part of the outer layers of the cortex of the "old brain" (paleocerebellar region) in one monkey and of the "new brain" (neocerebellar region) in the other. The monkey with the old-brain lesion became much more peaceful, while the one with the new-brain lesion did not. That result makes sense: the old-brain cerebellum connects primarily to the emotional centers in the limbic system, while the new-brain region connects primarily to the neocortical structures that regulate higher brain processes.

Meanwhile, Austin Riesen at the University of California, Riverside, demonstrated that isolation-reared monkeys exhibit major differences in the brain-cell branches of the somatosensory and motor cortex, but not in the visual cortex. And at the University of Illinois, Murray Floeter and William Greenough found that monkeys raised in colonies had more extensive brain-cell branchlets in parts of the cerebellum than monkeys reared either in isolation or in pairs.

Thus, the influence of the environment seems to be imprinted on the structure of the brain, which, in turn, shapes the environment. (I call this approach to studying behavior "ecobiology," to distinguish it from sociobiology.) In addition, cross-cultural studies have established a significant relationship between the physical affection shown human infants and rates of adult physical violence. In one study of 49 primitive cultures, I found that when levels of infant affection are low—as among the Comanches and the Ashanti—levels of violence are high; where physical affection is high—as among the Maori of New Zealand and the Balinese—violence is low. I also found that restrictions on premarital sexual affection were associated with high violence.

The possible lesson for modern countries is clear. We seem to be suffering from breakdowns in affectional bonds—reflected in everything from rates of divorce to sexual crimes, alcoholism, and drug abuse. Culture is the handmaiden of our neurobiology, and without a proper environment for physical affection, a peaceful, harmonious society may not be possible.

James W. Prescott is a developmental neuropsychologist with the National Institute of Child Health and Human Development. The views expressed here are his own and not necessarily those of the NICHHD.

STATEMENT OF DR. BLAIR E. BATSON, AMERICAN ACADEMY OF PEDIATRICS

Senator PROXMIRE. Now we'll continue with the National Institute of Child Health and Human Development with Dr. Blair Batson of the American Academy of Pediatrics.

Dr. BATSON. Mr. Chairman, I'm Dr. Blair Batson, a pediatrician at the University of Mississippi Medical Center. I'm here today representing the American Academy of Pediatrics.

I would like to highlight our recommendations for fiscal 1984 in four major areas: research, maternal and child health, block grants, the immunization program, and primary care training in pediatrics.

First, research. In a budgetary time marked by increasing concern with cost effectiveness, few areas of Federal expenditures are so readily cost justified as the Nation's investment in biomedical research sponsored by NIH. This is particularly true with respect to research benefiting mothers and children supported by the NICHD, for it is aimed primarily at preventing death, disease, and disability. Progress in these areas is threatened, however, by the reductions in NIH research activities that would result if the administration's budget were to be adopted.

In particular, the NICHD budget figures for fiscal year 1984 reflect a dismaying pattern of result years in which research in child health has received somewhat less support than other NIH research.

We recommend the funding for NICHD be set at approximately $281 million for fiscal 1984.

Second, the maternal and child health block grants. Programs in the MCH block provide grants to States to assure that poor mothers and children have access to quality MCH services. The President's proposal would perpetuate the significant cutbacks in the MCH block grant by maintaining the fiscal year 1983 dollar level, making no adjustments for inflation. Keeping funding constant would force States to continue policies under which 47 States cut back on MCH funding by reducing eligibility and/or health services.

In my own State of Mississippi, Federal set-aside funding for the improved child health projects which are located in areas where infant mortality is highest and which serve an estimated 10,000 to 12,000 patients per year will be terminated in fiscal year 1983, and it is anticipated there will be no alternative source of funding for these projects.

Under Public Law 98-8, Congress restored $105 million to the fiscal year 1983 budget for MCH. It is the purpose of these additional moneys to help ease some of the strain placed on these programs by earlier budget cutbacks and unemployment. In 1983 it is estimated that some 13 million children will be living in families experiencing joblessness. Most of these children, for a variety of reasons, will not qualify for medicaid. Hence, support for the MCH block grant program becomes critical. We recommend that funding for the MCH block grant be continued in fiscal 1984 at the adjusted 1983 level of $478 million.

Third, immunizations. Previous cuts in the childhood immunization program, along with sharp increases in cost of vaccine during recent years, have left far too many children unprotected against serious infectious diseases. The consequent cost to society is very high indeed. We recommend that the childhood immunization program be funded at $42 million for fiscal 1984, a roughly "no growth" sum, but sufficient to maintain the successes of recent years. And I point particularly at the most recent, the measles.

Finally, training. Total funding for general pediatric and general internal medicine primary care training programs was preferentially slashed in fiscal year 1983 from $16,200,000 to $11,300,000.

The case is simply put. According to officials at HHS, 36 pediatric and internal medicine training program applications have been approved by the Department for support this year, but fully two-thirds of them or more will not be funded because of the $4,900,000 cut.

The need for adequate support is pressing. Pediatricians have more time now to devote to what have been relatively neglected areas: chronic disease, behavioral problems of childhood and adolescence, and those increasingly prevalent health problems socially induced are complicated by social and environmental factors.

There has also been a dramatic increase in our recognition of child health problems associated with poverty, of deteriorating physical environment, changing family structure, and other social and psychological factors.

We ask Congress to authorize funds to allow the pediatric community to develop and maintain educational programs relevant to those needs. We recommend that for pediatric and internal medicine training programs a supplemental appropriation be considered in the sum of $4,900,000 to remedy the shortfall in the current fiscal year and at least the same overall amount which would ensue as a result, $16,200,000 be allocated for fiscal year 1984.

Thank you, Mr. Chairman.

Senator PROXMIRE. Thank you very, very much, Dr. Batson.

[The statement follows:]

STATEMENT OF DR. BLAIR E. BATSON

The year 1984 promises still further changes for children and for the pediatric programs that serve them. As pediatricians, we continue striving to meet these new challenges through research, through our residency training programs and through our practice methods. Yet we find ourselves at a crossroads. Budgetary restrictions, compounded by high unemployment, have placed serious strains on the various service and research programs designed to protect and promote the health of our nation's children. Sharp cutbacks in primary care training grants do additional damage to our efforts to meet tomorrow's needs.

RESEARCH

In a budgetary era marked by increasing concern with cost-effectiveness, few areas of federal expenditure are so readily cost-justified as the nation's investment in biomedical research sponsored by the National Institutes of Health. This is particularly the case with respect to research benefiting mothers and children supported by the National Institute of Child Health and Human Development (NICHD), for it is aimed at preventing death, disease and disability in the critical period at the beginning of human life and during the ensuing childhood years.

Research devoted to controlling diseases of infancy, diseases which all too often leave their victims handicapped for life, contributes mightily to one of the chief goals of medical science -- prevention. Even beyond the obvious human grounds on which increased funding for NICHD can be based, there are substantial savings to be had. Consider costs currently incurred by society in just a few of the areas being addressed by researchers in pediatrics:

- Babies born too soon or too small cost the American public at least $8 billion annually for intensive hospital treatment.

- Serious birth defects affect more than 150,000 children per year, costing billions of dollars in hospitalization, rehabilitation and custodial care that may last a lifetime. From 3 to 5 percent of all children born are affected with a serious birth defect.

- Abnormalities in learning capacity, including mental retardation, dyslexia and other disorders, require lifelong attention and result in unproductive lives. Each year, 100,000 children are newly diagnosed as mentally retarded. And as many as 15 percent of American students -- 1,200,000 children -- have dyslexia.

- Many major diseases of adulthood, such as high blood pressure, lung disorders, atherosclerosis and obesity, have origins in childhood.

Prevention of these major disorders, which could save billions of dollars in treatment, hospitalization and loss of work time, depends on efforts focused on early life. There are no instant breakthroughs to cope with these age-old problems that afflict children and their families, but there are promising advances. They must be spurred.

Progress in these areas is threatened, however, by the reductions in NIH research activity that would result if the Administration's budget were to be adopted. Appropriations for NIH, measured in nominal dollars, would be increased by the Administration in FY 1984 by about 1.8 percent, but this modest increase would not be matched by a corresponding increase in NIH research and training activities. Indeed, there has been a steady decline in the number of new and competing grants awarded by NIH, a decline that would be accelerated by the Administration budget.

This committee in 1979 established the goal of 5000 new and competing grants to be funded each year, while maintaining a level of 15,000 total research grants (H. Rpt. 96-244, p. 26). The President's budget falls far short of this goal, with only 3770 new and competing grants and 9100 trainees projected for FY 1984. This shortsighted reduction threatens the long-term prospects of meeting our professed national commitment to strengthening research capabilities.

Because research in pediatrics is supported by a number of institutes, our remarks have been addressed to the funding for all of NIH. We obviously have a special concern, though, for NICHD, and for the especially severe impact the budget would have on it. The NICHD budget figures for FY 1984 reflect the pattern in recent years in which research in child health has received less support than other NIH research areas. It is appalling from a moral and economic standpoint that the one area which has suffered most consistently from neglect has been research at NICHD related to women, children and families -- research, in fact, that has perhaps the greatest potential for cost savings.

> RECOMMENDATION: That in order for NICHD to keep pace with other institutes at NIH, particularly in the area of approved grants, funding for NICHD be set at $283,465 for fiscal 1984.

MATERNAL AND CHILD HEALTH BLOCK GRANT

Programs in the maternal and child health block provide grants to states to assure that mothers and children (particularly those with low income or with limited availability to health services) have access to quality maternal and child health services. Efforts are directed at reducing infant mortality and the incidence of preventable diseases and handicapping conditions; at providing preventive services such as immunizations and health assessments for low-income children; at quality prenatal, delivery and post-partum services, and at rehabilitation services for blind and disabled SSI children. Moreover, a percentage of the funds is set aside for projects of regional significance, including research and training for genetic disease testing, counseling and information development, and hemophilia and diagnostic treatment centers.

The President's proposal would perpetuate the significant cutbacks in the MCH block grant by maintaining the FY 83 dollar levels, making no adjustments for inflation. Keeping funding constant would force states to continue policies under which 47 states (94 percent) cut back on maternal and child health funding by reducing eligibility and/or health services.

Under P.L. 98-8, Congress restored $105 million to the fiscal 1983 budget for maternal and child health. It was the purpose of these additional monies to help ease some of the strain placed on these programs by earlier budget cutbacks and the unemployment factor. In 1983 it is estimated some 13 million children will be living in families experiencing joblessness, and most of these children, for a variety of reasons, will not qualify for Medicaid. Hence, support for the MCH block grant programs becomes critical.

> RECOMMENDATION: That funding for the maternal and child health'block grant be continued into fiscal 1984 at the adjusted 1983 level of $478 million.

IMMUNIZATIONS

Previous cuts in the childhood Immunization Program, along with sharp increases in the cost of vaccine during recent years, have left far too many children unprotected against serious infectious diseases. The consequent cost to society of this shortsightedness, let alone the unnecessary personal tragedies, is staggering. By way of illustration, consider merely the most recent rubella (German measles) epidemic: it affected 30,000 children, many seriously, and required $2 billion in special care.

The child health community thus requests that Congress set aside $42 million for childhood immunizations during fiscal 1984, a modest increase over current funding that essentially would continue the program at its current level. To allocate less flies in the face of compelling documentation that indicates an inverse relationship between federal support for vaccine programs and the incidence of diseases at issue (namely, polio, mumps, measles). Fairer funding means fewer cares -- indeed, it is estimated that immunizations against measles alone yield a $10 benefit for every $1 the government spends. Lives are saved; cases of mental retardation are prevented; hospital days and physician visits are averted.

Well worth underlining is that within three years of the onset of federal support for childhood immunizations in 1966 the United States enjoyed a 90 percent reduction in reported cases of measles. But funding for the program was cut in 1969. The result: the number of measles cases doubled in 1970 and tripled in 1971. Only when adequate federal funding was restored the following year did reasonable control of the disease resume. Two years ago a record low was reached, and the elimination of indigenous measles in this country now looms as an attainable goal.

Our society simply cannot afford, morally or economically, to turn its back on the 3.5 million children born here each year. Tightfistedness, however pressing short-term budget constraints might be, could prove costly and cruel -- costly in direct dollar terms to all of our citizens for many years to come, and cruel to the unfortunate victims and their families for a lifetime. No one can quantify the pain associated with these illnesses. Deafness, blindness, cerebral palsy, retardation and severe emotional disturbance can destroy children and their families. When the capacity to prevent these conditions is at hand, failure to protect our citizens is doubly cruel.

> **RECOMMENDATION:** That the federal Childhood Immunization Program be funded at $42 million for fiscal 1984, a roughly "no growth" sum, but sufficient to meet immediate national needs.

TRAINING

Last year we submitted for your consideration our strongly held view that entirely apart from the clear importance and established efficacy of pediatric training programs, no primary care specialty should suffer arbitrarily disproportionate federal assistance during a period of such scarce resources. Yet total funding for general pediatric and general internal medicine primary care training programs was especially slashed in fiscal 1983 from $16.2 million to $11.3 million, an action with directly detrimental consequences for the quality of health care in many communities.

The case is simply put. According to officials at HHS, 36 pediatric and internal medicine training program applications have been approved by the Department for support this year -- but fully two-thirds of them or more will not be funded because of the $4.9 million cut. This circumstance never before has arisen. There always have been sufficient resources in the past for the federal government to assist training programs of proven effectiveness. We urge that the committee consider a supplemental appropriation at once in the sum of $4.9 million to remedy the shortfall this year, and that at least the same overall amount ($16.2 million) be allocated for fiscal 1984.

The need for adequate support is pressing. Advances in prevention and control of traditional acute and infectious diseases permit the pediatrician to devote more time and attention to what have been relatively neglected areas: chronic disease; the increasing number of behavioral problems of childhood and adolescence; and what we call biosocial problems, those health problems socially induced or complicated by social and environmental factors. Because coping with the challenges of modern society will cause an increase in the incidence of biosocial problems, modern pediatric training must be directed more specifically to the treatment of those problems.

There has been also a dramatic increase in our recognition of child health problems associated with poverty, a deteriorating physical environment, changing family structures and other social and psychological factors. There is growing evidence that encouragement of health promotion and changes in life-styles may become more important than medical intervention in affecting morbidity and mortality. The pediatric community recognizes that pediatric education must respond to these changes in child health needs. We ask Congress to follow suit by authorizing the funds to allow us to develop and maintain and educational program relevant to those needs.

By the completion of formal postgraduate training, most pediatricians are extraordinarily skilled at diagnosing and managing illness, especially that of hospitalized children. As a consequence of concentrating pediatric resident education on illness, many [illegible] not most pediatric residents have only a rudimentary knowledge of the concept of normality and particularly of the variability surrounding the "average" with regard to child development and health status.

In the future, pediatricians will be called upon more and more to manage children with emotional disturbances, learning disabilities, chronic illnesses and other problems of a developmental, psychological and social nature. They will provide increased amounts of health care to adolescents. They will be expected to manage their practices efficiently, collaborate with other members of the health care team and use community resources to enhance the effectiveness of services to children and their families.

The ambulatory experience responds to these needs by developing skills in counseling, anticipatory guidance, developmental appraisal, referral, consultation, use of screening procedures and practice management. Skills relating to the care of children with chronic illnesses and handicapping conditions are particularly important. Finally, the ability to coordinate services, plan comprehensive care and mobilize available community resources is essential to provide ambulatory care of high quality. To accomplish all this, there remains a distinct need for faculty development and greater support for research related to ambulatory care. Full-time faculty members in ambulatory pediatrics need formal training in the discipline; it is no longer acceptable to assume that any pediatrician can teach ambulatory pediatrics.

Unfortunately, the pediatric community finds itself in the unenviable position of responding to a dramatic shift in educational need in an atmosphere of fiscal restraint. Moreover, increasingly larger percentages of medical school funds are being devoted to the delivery of patient care, a development which we recognize is a justified response to the public demand for quality health but one which means that other sources of support are necessary if service programs in educational centers are to improve the teaching environment -- particularly through the development of model ambulatory care programs. An appropriate program of grants for general pediatric training could respond to this need by earmarking funds for the development of ambulatory pediatric models.

> RECOMMENDATION: That for pediatric and internal medicine training programs a supplemental appropriation be considered at once in the sum of $4.9 million to remedy the shortfall in the current fiscal year, and that at least the same overall amount which would ensue as a result ($16.2 million) be allocated for fiscal 1984.

STATEMENT OF JEAN A. CORTNER, M.D., CHAIRMAN, DEPARTMENT OF PEDIATRICS, UNIVERSITY OF PENNSYLVANIA, ON BEHALF OF THE AMERICAN PEDIATRIC SOCIETY, ASSOCIATION OF MEDICAL SCHOOL PEDIATRIC DEPARTMENT CHAIRMEN AND SOCIETY FOR PEDIATRIC RESEARCH

Senator PROXMIRE. Our next witness is Dr. Jean Cortner, chairman of the Department of Pediatrics, University of Pennsylvania on behalf of the American Pediatric Society, Association of Medical School Pediatric Chairmen and Society for Pediatric Research. Dr. Cortner.

Dr. CORTNER. Thank you, Mr. Chairman. I represent three societies, the Society for Pediatric Research, the American Pediatric Society, and the Association for Medical School Pediatric Department Chairmen.

These three organizations represent virtually all physicians and scientists doing pediatric research.

As pediatricians, we are obviously particularly interested in the beginning of life and health and development throughout childhood years, so we have broad interests in science and research, including cancer, human nutrition, infectious disease, genetics, and the cardiovascular system, among others.

My own research is in the area of recognition and prevention of atherosclerosis starting in childhood.

Although we are here today primarily to speak to the needs of the National Institute of Child Health and Human Development, we have a broader interest in the stability and progress of the entire National Institutes of Health research and training programs, and we are appalled at the administration's fiscal year 1984 budget.

The initial budget reduced the number of new and competing grants that could be awarded by 25 percent from 4,914 to 3,676 and the training slots from 10,000 to 9,100. The consensus has been reached for several years in Congress and the NIH and research organizations that 5,000 new and competing grants annually is an absolute minimum in terms of the stability of the National Institutes of Health and 10,000 research training positions in terms of building our basic future researchers.

This has been referred to as a stabilization policy and was even recognized by the administration, and they purported then, when they came back with a new NIH budget, to have 5,000 new and competing grants. But this turns out to be a sham and the $141 million necessary to fund those grants has been stripped from other NIH programs. Both new and existing grants would be subjected to across-the-board decreases and direct and indirect costs, intramural research, contract research, the very important biomedical research support grant research, which is particularly necessary for young investigators, all would be substantially reduced.

Perhaps most arbitrarily, some 51 center grants would be terminated, which was spoken to by Dr. Talbot not because of merit, but simply because their cycle happens to come up in fiscal year 1984 and, therefore, they would be the ones that would be shut down.

I think that this is a mockery of the stabilization policy on the administration's part, and while we, as scientists, certainly recognize that the investigator-initiated grant should be given top priority, we do not think that the administration should be allowed to cannibalize all of NIH in the process of this stabilization.

The solution, of course, is to provide the additional funds needed to fully fund the desired number of grants.

The pediatric research organizations that we are a part of, recommend an increase of $487 million over the current year budget of NIH to achieve this end. This would permit the funding of the 5,000 new competing grants, and the 10,000 research training positions. It would also permit funding of NICHD of $281,600,000.

I will cut my testimony short at this point and say only that there are very important areas of research being done by the National Institute of Child Health and Human Development. They played a leading role in the revolution of molecular genetics. There are many, many areas of research that are increasing the quality of life, as well as the length of life.

It is a legacy that we should pass on to our children, and for these reasons, the pediatric research societies recommend to you the funding as listed in the document.

Senator PROXMIRE. Thank you, Dr. Cortner very, very much. And I apologize again for the brevity, for the 5-minute rule.

Dr. CORTNER. We're glad to be here.

PREPARED STATEMENT

Senator PROXMIRE. Thank you,. We will place your prepared statement in the record at this point.

[The statement follows:]

STATEMENT OF DR. JEAN A. CORTNER

My name is Dr. Jean A. Cortner. I am Professor and Chairman of the Department of Pediatrics at the University of Pennsylvania. I am here today representing the American Pediatric Society, the Society for Pediatric Research, and the Association of Medical School Pediatric Department Chairmen. These three organizations represent virtually every physician and scientist engaged in pediatric research in this country.

As pediatricians, we are concerned with events at the beginning of life and the health and development of individuals through the childhood years. These remain our primary concerns as areas of research, but among the organizations I represent today there are also scientists engaged in a broad range of research pursuits including, to cite only a few, studies relating to cancer, human nutrition, infectious diseases, genetics and the cardiovascular system.

Thus, while we emphasize the funding needs of the National Institute of Child Health and Human Development (NICHD) as the focus of research and training in pediatrics at the National Institutes of Health, we also have a broader interest in the stability and progress of the entire NIH research and training enterprise. And, like all who have an interest in the NIH, we are appalled by the Administration's funding proposals for Fiscal Year 1984.

The entire budget process as respects NIH has been marked by confusion, disarray and, finally, deception. The initial budget submitted by the President reduced the number of new and competing grants that could be awarded by about 25%, from an estimated 4914 this year to 3676 next year. Research training slots would decline from about 10,000 to 9,100. These are key measures of both the vigor and the stability of the NIH program; they indicate whether the grants system is open to new ideas and new people, and also whether there is a steady and predictable level of support from year to year. There has been a consensus in recent years at NIH, in Congress and among research organizations that, at a minimum, NIH should have the resources to award 5,000 new and competing grants annually and to fund 10,000 research training positions. This has been referred to as a "stabilization policy."

The validity of this consensus view was acknowledged by the Administration last month when it was forced to revise its clearly unacceptable budget for NIH. In its revised budget, the Administration purported to provide for 5,000 new and competing grants in FY 1984 (although no increase was provided for training). As I am sure you are now well aware, this supposed increase is a sham, for it would be accompanied by no additional dollars. Rather, the $141 million necessary to fund 5,000 new grants was stripped from other NIH programs. Both new and existing grants would be subjected to across-the-board percentage reductions of direct and indirect costs. Intramural research, contract research and the important Biomedical Research Support Grant program in the Division of Research Resources would be substantially reduced. Perhaps most arbitrarily, some fifty-one center grant programs would be terminated--not for lack of scientific merit, but merely because of the luck of the draw, for these grants happen to have expiration dates requiring renewal in FY 1984 and the Administration proposes no such center grant renewals in FY 1984.

Mr. Chairman, the Administration is making a mockery of the well-intentioned stabilization policy developed over the last several years. The implicit premise of any policy that provides for a minimum number of new research project grants and training grants to be awarded annually is that such awards be in addition to the remaining, ongoing NIH programs. While we as scientists certainly agree that investigator-initiated grants should be given the top priority, we cannot agree that the Administration may cannibalize all of NIH in the name of "stabilization."

The solution, of course, is to provide the additional funds needed to fully fund the desired number of grants. The Pediatrics Research Societies for which I speak are part of a coalition of organizations recommending an increase of $487 million over the current year budget for NIH ($414 million over the Administration budget) to achieve this end. Funding at this level will permit payment of full direct and indirect costs of renewal grants and slightly more than 5,000 new and competing grants; 10,000 research training positions would be available; the President's proposed instrumentation program would be expanded by $8 million; and some modest growth would be permitted in other areas.

Funding of the total NIH program in this amount would also permit an appropriation for NICHD in the amount of $281.6 million, an increase of 11% or $27.95 million over FY 1983 ($25 million over the Administration budget). We believe that this amount for NICHD is fully justified for the important research being carried on at the Institute warrants continued, and expanded, support.

Let me give just one or two examples of the work that the Institute is supporting that holds the prospect for better child health. Keep in mind, also, that many of the major adult diseases have their origins in conditions that first develop in infancy and childhood, so that better child health means better adult health, as well.

The infant delivered with a low birth weight is at great risk, for intrauterine growth retardation, which results in low birth weight, is a major cause of infant mortality and morbidity. It is known that fetuses ingest amniotic fluid. Researchers supported by NICHD have added specific nutrients to the amniotic fluid of pregnant sheep and thereby reversed known conditions of fetal growth retardation. This research may eventually lead to nutritional therapy for human fetuses in the womb, before delivery, to avoid the problems associated with low birth weight.

Such an advance is consistent with other research developments in which the approach is to treat fetal defects in utero where possible. The most dramatic developments in this area have been in fetal surgery. Surgeons working on an experimental basis have partially removed animal fetuses from the womb, performed corrective surgery, and returned the fetus to the womb to await normal birth. Fetal surgery has been performed on human fetuses without removal from the womb to correct hydrocephalus, the collection of fluid in the brain of the fetus, which usually causes severe retardation. Surgeons have inserted drains into the skulls of hydrocephalic fetuses, thereby reversing the defect in utero.

Such fetal therapy has so far proceeded on an experimental basis, but it soon will become a part of medical practice, thanks to the research that has shown the way.

Support for such research can properly be viewed as an investment, rather than an expenditure. In addition to the incalculable human values that result when mental retardation or other life-long problems are avoided through treatment of fetuses before birth or infants following birth, there is also an obvious and significant economic benefit. Rather than having to support damaged individuals for life at great cost, frequently through institutionalization, society enjoys the benefits provided by functioning, working citizens. It is estimated that each dollar invested in medical research produces $13 in savings resulting from reduced incidence of illness and reduced medical costs. I suspect that the savings derived from research in pediatrics is even greater, for the advances that result therefrom are at the center of preventive medicine.

For these reasons, the Pediatrics Research Societies urge the Subcommittee to approve a budget for NIH of $4.492 billion, an increase of $487 million over FY 1983, and a budget for NICHD of $281.6 million, for an increase of 28 million.

Supplemental Appropriations - FY 1983

We would also like to direct your attention to severe cuts that were made in the FY 1983 budget in Internal Medicine and Pediatric Training Programs. These important programs were slashed from $16.2 million in FY 1982 to $11.3 in FY 1983. This reduction will be felt in the number of applications approved but not funded this year. According to HHS, of the 68 applications received, 36 were approved. However, it is estimated that only 8-12 of these programs will be funded because of the budget cuts.

We strongly urge you to consider a supplemental appropriation of $4.9 million for FY 1983 to restore the funding level for this program to $16.2 million. We also request that you consider funding the program for FY 1984 at this same level of $16.2 million.

STATEMENT OF CHARLES F. BARLOW, M.D., PROFESSOR OF NEUROLOGY, HARVARD MEDICAL SCHOOL, NEUROLOGIST-IN-CHIEF, CHILDREN'S HOSPITAL MEDICAL CENTER, DIRECTOR, MENTAL RETARDATION RESEARCH CENTER, CHILDREN'S HOSPITAL, BOSTON, MASS., ON BEHALF OF THE NATIONAL MENTAL RETARDATION RESEARCH CENTER DIRECTORS

Senator PROXMIRE. Our next speaker is Dr. Charles Barlow, neurologist-in-chief, Harvard University Department of Neurology, and chairman of the Mental Retardation Research Program Center Directors.

Dr. BARLOW. Thank you, Senator Proxmire. Good morning. You're right. I am the professor of neurology at Harvard Medical School, neurologist-in-chief of Children's Hospital in Boston, and director of the Mental Retardation Research Center there, one of approximately a dozen such centers over the country.

In my testimony today, I represent that national network. I think I also represent and speak for mentally retarded people, their families and future Americans who will be the chief beneficiaries of these efforts.

Manifestations of mental retardation are significant impairments to learning, social development, and ability to live independently. There are approximately 6 million retarded persons in the United States today, and if the prevalence of them in the United States were the same today as it was in 1960, there would be 7 million. And the difference represents a very real achievement to date. The economic costs are also considerable. Just to provide for the 130,000 retarded persons who must reside in public institutions costs about $3,500,000,000 per year or an average of $25,000 per person. The cost of educating an educable retarded individual to age 21 is more than six times the regular pupil cost of public education. The only reasonable course is to work as hard as we can to learn to prevent mental retardation as well as to ameliorate its effects when it does occur.

Our national goal as enunciated in the early 1970's by the President's Commission was that by the year 2000, the incidence of MR would be reduced by one-half. That goal has not changed.

Where do we stand today? My colleague at Children's Hospital, Dr. Allen Crocker, who heads our training and service program in MR and is currently president of the university affiliated programs for the developmentally disabled, has recently reviewed the state-of-the-art from the perspective of prevention and has cited 20 activities which can reduce the incidence of MR by 20 to 30 percent.

The work is going forward. It is in the national interest.

I support the recommendation you just heard that $487 million be added to the NIH budget. The defense of that statement was eloquently stated. Also, we recommend that appropriations for NICHD be increased 10 percent for fiscal year 1984 to $279 million. Of these funds, we request the following:

First, that an amount of $8 million be identified as a special item for MR center core grant support. The essential glue of these centers has been the system of periodically reviewed core grants, which serves to maintain cost-effective resource laboratories, common facilities used by many investigators, and to effect new initiatives.

From the Federal perspective, the competing renewal of these core grants is a system of reviewing the overall scientific excellence of the research of the centers and of the relevance to mental retardation. Without the safeguard of overview based on core grant review, even with the best intention, there could be some drift in the overall excellence or the relevance of the centers. The 1983 allocation was $7 million, which did not include one of the originally constructed centers whose program is not currently receiving core support.

The level of core funding has been essentially flat since 1977, and the current level is over $1,500,000 below the amount which has been approved on scientific merit review. If the recently presented proposal of $6,300,000 for core support is accepted, we may lose three more centers. This would be fatal to the national network, with reduction, perhaps elimination, of a total of one-third of their numbers.

Without the central feature of core program support, centers will lose their cohesion, their glue. The national thrust would surely falter.

Second, we feel that an amount of $22,500,000 be allocated to support an immediate increase in scientifically meritorious research projects directly related to mental retardation. At this moment, there are at least 30 to 40 such projects which are ready to go.

Finally, we request that 50 percent of the remaining additional funds be utilized in strengthening support of research in basic developmental neurobiology. This is a very real investment in the future. How else will we ever learn how the nervous system is put together, what has made it go astray in several million Americans and what can be done to prevent this outrageous trick of nature.

MR centers, I believe, represent a collaborative effort of the universities and the Federal Government, which has been a noble, cost effective, and successful experiment. They are the focus of research attention on a highly significant human problem which also has broad biological significance. There has been a measure of success, and I urge that there be continuing support to NICHD and centers to enable them to carry out their work.

Thank you, Senator.

Senator PROXMIRE. Thank you, Dr. Barlow. We very much appreciate it.

[The statement follows:]

STATEMENT OF CHARLES F. BARLOW

This statement is prepared in support of the programs of the National Institute of Child Health and Human Development, and especially in support of its programs of research on the causes, prevention and amelioration of the problem of Mental Retardation, and of its research efforts in the relevant related fields of basic developmental neurobiology and neurobiologic research.

The principal focus of research on mental retardation within the NICHD has been a network of Mental Retardation Research Centers which, together with university affiliated clinical training and service facilities, (University Affiliated Programs) were constructed as a result of public law 88-164, "The Mental Retardation Facilities in Community Mental Health Centers Construction Act of 1963". As a result of that legislation there were 12 MR Research Centers established, which are located in California, Colorado, Illinois, Kansas, Massachusetts, New York, North Carolina, Ohio, Tennessee, Washington and Wisconsin. The Mental Retardation Research Centers were constructed in the late 1960's and early 1970's with a commitment to a 20-year program of research and training in mental retardation and related aspects of human development. The institutional commitment included matching funds for construction grants, staffing in the form of tenured faculty positions and other supports for the programs of research. Continued federal support has been forthcoming in the form of Core Grants administered by NICHD on competitive peer review plus project and program-project grants which have been awarded by NICHD and other Institutes as well as private foundations.

The essential glue of these Centers has been the system of periodically reviewed Core grants which serve many purposes. From the perspective of the Centers, funding is made available to maintain cost-effective resource laboratories which support common facilities used by many investigators and to effect new initiatives, etc. From the federal perspective the competing renewal of these Core grants is a system of reviewing the overall scientific excellence of the research of the centers, the relevance to MR and proper utilization of facilities, collaborative opportunities, etc. Without the safeguard of overview based on Core grant review, even with the best intentions, there could be some "drift" in the overall excellence or relevance of the centers. The MR Centers have taken their role as a national network seriously. The directors meet two times per year, usually one time with their U.A.P. colleagues to discuss mutual problems, communicate research progress, etc.

The national network of MR Research Centers in the aggregate have addressed the broad front of biological and clinical problems which are the basis of mental retardation in the patient. Another point of emphasis is the behavioral/social/

educational research programs which deal with an effort to understand the psychosocial functioning of persons who are already retarded, i.e. to ameliorate the effects of retardation in those individuals who have been affected. Because the work is focused, often collaborative across disciplines and closely related in spirit and function to the training and service facilities (UAP), the results of these efforts is greater than the sum of their parts. The biological approach of the problem has correctly emphasized the understanding of causation and pathogenesis with the aim of prevention because the central nervous system is more refractory than any other tissue in its regenerative capacity. It should be recognized that success in these endeavors will be "invisible" because our patients will tend to disappear. Our national goal, as enunciated in the early 70's by the President's Commission, was that by year 2000 the incidence of mental retardation would be reduced by one half. This goal has not changed.

Nature and Scope of the Problem: Mental retardation is a lifelong problem associated with well over 200 known causes. In a majority of patients the cause is not known and this is the crux of the problem.

Table 1

The following rough diagnostic breakdown of 2,000 patients seen by the Developmental Evaluation Clinic of Children's Hospital Medical Center in Boston, provided by Dr. Allen Crocker, expresses a fair estimate of the incidence of major diagnostic groupings.

I.	Hereditary issues (inborn metabolic errors, phakomatosis, familial retardation)	4%
II.	Early influences on embryonic development--dysgenesis (sporadic chromosomal abnormalities, multiple congenital anomalies, also includes prenatal infectious processes)	33%
III.	Perinatal morbidity (asphyxia, prematurity)	12%
IV.	Acquired childhood diseases (head trauma, meningitis, encephalitis)	4%
V.	Environmental and social problems (psychosocial deprivation, psychosis, and autism)	19%
VI.	Unknown causes (borderline to mild, 2/3; moderate to profound, 1/3; the latter probably including many with cerebral dysgenesis)	28%

Reference: Barlow, C.F. Mental Retardation and Related Disorders, F.A. Davis, Company, Philadelphia, 1978. P4

My colleagueat Children's Hospital, Dr. Allen Crocker, who heads our training and service program in MR and is the current President of the University Affiliated Programs has recently reviewed the "state of the art" from the perspective of prevention and has cited 20 activities which can reduce the incidence of MR by 20-30%.*

The principal manifestations of MR are significant impairments to learning, social development and ability to live independently. There are approximately 6,600,000 retarded persons in the United States today (if the prevalence of mental retardation in the U.S. were the same today as it was in 1970 there would be 7,600,000 mentally retarded persons in our current population, and the difference represents very significant achievement to date). Because mental retardation is a family tragedy and parents and brothers and sisters are impacted, one can estimate that 33,000,000 persons in the American population are touched directly by the problem in their immediate family. The cost in terms of human tragedy can only be fully known by the patients and their families, but it is great.

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*Crocker, A.C., Current Strategies in Prevention of Mental Retardation, Pediatric Annals 11(5):450-457, 1982

The economic costs are also staggering. Just to provide for institutionalization of 130,000 retarded persons who must reside in public institutions costs about $3.5 billion per year or an average of $25,000 per person. The cost of educating an educable retarded child to age 21 is more than six times the regular per pupil cost of public education. The only reasonable course is to work as hard as we can to learn to prevent mental retardation as well as to ameliorate its effects when it does occur. These are the goals of the mental retardation community and of the national network of MR Research Centers.

Selected Accomplishments of the Immediate Past Year of the MR Research Centers:

Space does not permit an extensive discussion of recent progress. My colleague Dr. Baumeister will deal with advances in behavioral research, while I shall mention several illustrative examples of biomedical progress. Animal studies have indicated that the serum of monkey mothers who have a history of high risk pregnancies adversely affects the growth of rat embryos as compared with serum from monkeys with a good pregnancy record. It has also been shown that binge alcohol consumption during pregnancy by the monkey has as adverse an effect on the fetus as steady consumption, while epidemiologic studies in the human indicate that even a past history of alcoholism is associated with an increased incidence of MR in subsequent offspring. An implantable glucose sensor has been developed at the Cincinnati Center which may be adaptable to the detection of blood sugar levels thru the skin. This would be a significant advance in the management of the newborn baby whose blood sugar levels are unstable, and low sugar in the newborn is a significant cause of brain damage. Progress has been made in the development of biodegradable polymers which form tubular channels to provide a track for regenerating nerve fibres. The Alzheimer dementia which develops in Down Syndrome patients has been characterized, and a new focused center on "The Biology of Down Syndrome" has been established at U. Cal., San Francisco.

Research Problems of the Present and Immediate Future.

1. The highest priority should be placed on better understanding of the basic science of the development and function of the nervous system, (Neurobiology), the causes of abnormal development (Teratology), and the inherited influences on both (Genetics). These areas represent at least 50% of the problem of MR today and impact on many other birth defects as well. An immediate teratologic problem which is a practical spin off of a successful detection and treatment program of the past is the issue of the PKU mother (an individual treated from very early life with dietary management and who is now normal, coming of age and beginning to think of marriage and families). It is clear that her residual asymptomatic metabolic defect adversely effects the development of her baby. There is an extraordinarily high incidence of mental retardation and other congenital anomalies in the babies who do not themselves have PKU. The management of such pregnancies is an urgent problem which is currently being addressed by a proposed multicenter study under the aegis of the Mental Retardation Branch of NICHD. This issue also poses an important set of basic neurobiologic questions which can be addressed in the laboratory. For example, do other normal people have an asymptomatic inborn metabolic error which affects fetal brain development, and where and how does it act?

2. The problem of brain damage in the period around the time of birth, especially the prematurely born, represents one of the triumphs of the recent past, which has resulted in a major decrease in MR and certain Cerebral Palsies. It is also a continuing challenge for the future. With the effective management of the cardiorespiratory system in these tiny babies, a different set of neurological problems have assumed prominence, such as bleeding into the brain cavities, and brain damaging low blood sugar. Both may be relatively "silent" from the point of view of symptoms, and both occur in the first few days of life so they provide a significant opportunity for prevention of brain damage. What is lacking is understanding of cause in the intracranial hemorrhage problem and a simple universally applicable method of monitoring blood sugar with respect to the hypoglycemia issue.

3. Behavioral research is faced with the continuing problem of early detection, and of developing educational methods to minimize a handicap related to the degree of disability which range from dyslexia and mild learning problems to the training of the more severely handicapped. The later life management problems of families and the retarded person are continuing issues which involve considerations of residential, work and family placement.

Our recommendations are as follows:

1. Appropriations for NICHD be increased 10% for fiscal year 1984 to $279,021,000 over the fiscal 1983 budget of $253,655,000 (Administration request for fiscal 84 is $257,348,000).

2. Of these funds we request that:

   A. An amount of $8,000,000 be identified as a special item for MRRC core grant support.

   B. An amount of $2,500,000 be allocated to support an immediate increase in scientifically meritorious research projects directly related to mental retardation.

   C. That 50% of the remaining additional funds be utilized in strengthening support of research in basic developmental neurobiology and mental retardation in general.

In summary, we need the encouragement and support of the Congress with full recognition that the "blank check" era of research is over. There is no doubt in my own mind that the MR Research Centers represent a collaborative effort of the Universities and the Federal Government which has been a noble, cost effective and successful experiment. They have formed the focus of research attention on a highly significant human problem which has broad biological significance. There has been a measure of success, and I urge that there be continuing support to NICHD and the Centers to enable them to carry out their mission.

STATEMENT OF ALFRED A. BAUMEISTER, PROFESSOR OF PSYCHOLOGY, JOHN F. KENNEDY CENTER FOR RESEARCH ON EDUCATION AND HUMAN DEVELOPMENT, VANDERBILT UNIVERSITY ON BEHALF OF THE AMERICAN ASSOCIATION ON MENTAL DEFICIENCY, THE AMERICAN ACADEMY ON MENTAL RETARDATION AND THE AMERICAN PSYCHOLOGICAL ASSOCIATION, DIVISION ON MENTAL RETARDATION

Senator PROXMIRE. The final witness is Dr. Alfred A. Baumeister, professor of psychology, Kennedy Center for Research on Education and Human Development, George Peabody College for Teachers, also representing the American Association on Mental Deficiency, the American Psychological Association and the American Academy of Mental Retardation.

Dr. BAUMEISTER. Thank you, Mr. Chairman. My name is Al Baumeister. I am the director of the Kennedy Center at Vanderbilt University, one of the 12 national mental retardation centers, a group which includes the one in Wisconsin, which is undergoing review this very day.

I do represent the American Association of Mental Deficiency, the American Academy on Mental Retardation, and the American Psychological Association.

We are grateful for this opportunity to talk about NICHD with particular relevance to mental retardation research.

Mental retardation is a lifelong behavioral phenomenon with social, psychological, and biological causes. We can identify over 200 different etiologies that cause mental retardation. The human and the financial costs associated with mental retardation are absolutely staggering. Dr. Barlow spoke about part of those costs and they're just a fraction. No other human affliction creates so much suffering for so long, at such great cost to the individual, the family, the community, and our Nation.

There are approximately 6,600,000 retarded persons in the United States today and about one out of every six families is directly affected.

It is a complex problem, but despite these complexities, we have made progress toward the twin goals of amelioration and prevention. Much of this knowledge has been put into practice with very good results. And without the continuing support of Congress these accomplishments would not have been possible. Yet since 1974, the commitment to mental retardation research has deteriorated, and if this trend continues, it will be extremely serious with regard to our research effort.

Dr. Berkson and I have conducted various types of analyses of NICHD funding patterns. The one general and compelling conclusion that emerges from these analyses is that mental retardation, both in absolute and relative terms is in a much less favorable position today as compared to 10 years ago.

The mental retardation research centers have been particularly hard-hit. And attached to my written testimony is a graph that shows this regular and continuing decline in mental retardation and research support from 1972 to 1982. In 1982, 33 NICHD grants were approved through peer review with excellent priority scores, but could not be funded.

These projects covered an extremely important range of issues. For example, a number dealt with problems of Down's Syndrome and developmental neurobiology. The total amount of money requested for those projects came to $2.4 million. The scientific knowledge lost because those projects could not be undertaken is tragic.

We respectfully encourage the Congress to increase appropriations to NICHD to a level that insures the continuity of research and research training programs and at a level that begins to redress the decline in funding for mental retardation research about which I spoke earlier.

Our specific recommendations are as follows:

One, we urge the Congress to increase funding by 10 percent to the NICHD from $254 million in the current fiscal year to $279 million in fiscal year 1984. This is in contrast to the administration request of $257 million.

Two, that the mental retardation research centers be designated as a special item in the budget and that $8 million be appropriated for core support for these centers. The centers are a unique scientific resource and the evidence is certainly clear that they continue to produce research of the highest quality. Their future, as you well know, Mr. Chairman, is threatened.

Three, that report language indicate that $2,500,000 of the increase be designated for support of regular research grants of high quality.

Four, that report language indicate congressional intent for half the increase, or $12,500,000, be directed for research in the general area of developmental neurobiology.

Five, that the Congress express its commitment to high quality predoctoral and postdoctoral research training.

I thank you, sir.

Senator PROXMIRE. Well, thank you very much, Dr. Baumeister. I might just point out that you have a real champion in the chairman of the subcommittee, Senator Weicker.

Dr. BAUMEISTER. Thank you.

Senator PROXMIRE. I don't think anybody in the Congress of the United States in either body has been more concerned about this or active or more sympathetic. And I am sure that your recommendation and that of Dr. Barlow and others will certainly be given every consideration by the chairman.

Dr. BAUMEISTER. We thank you, sir.

Senator PROXMIRE. Your statement will be included in the record at this point, along with other statements submitted for the record on appropriations for the National Institute of Child Health and Human Development.

[The statements follow:]

STATEMENT OF ALFRED A. BAUMEISTER

Mr. Chairman, my name is Alfred Baumeister. I am the Director of the John F. Kennedy Center at Vanderbilt University, one of the 12 national Mental Retardation Research Centers constructed and established under the provision of Public Law 88-164. Appearing here today I represent the American Association on Mental Deficiency, the American Academy on Mental Retardation, and the American Psychological Association, Division on Mental Retardation. These are all professional organizations dedicated to solution of the problems of mental retardation and related disabilities. Speaking in behalf of my many colleagues in these various organizations, I am grateful for the opportunity to share our views concerning federal support, through NICHD, for research on mental retardation and related disabilities.

Mental retardation is a life-long behavioral phenomenon with social, psychological, and biological causes. The principal manifestations are significant impairments to learning, social and physical development, and the ability to live independently. Over 200 different etiologic causes are associated with mental retardation including genetic conditions, disorders of metabolism, problems of pregnancy and birth, brain damage due to a large number of teratogens, accidents, and other untoward circumstances that affect development such as extensive poverty, undernutrition, and lack of adequate psychological and social stimulation. Even in many of those cases where we have some knowledge as to cause, we know little about how to prevent or cure. For the great majority of cases, even the causes are not known. It is hard to prevent conditions about which do not know the causes.

The human and financial costs to society of mental retardation and the other developmental are staggering. No other human affliction creates so much suffering, for so long, and at such great cost to the individual, the family, the community, and our nation. There are approximately 6,600,000 retarded persons in the United States today and about one out of every 6 or 7 families is directly affected. Just to provide care and habilitation to the 130,000 retarded persons who reside in public institutions, government will spend about 3.5 billion dollars this year. The average cost to the public is over $1,000,000 over the life time of each retarded individual. The cost of education of a retarded child in the public schools is about six times the amount expended on the education of a nonretarded child. The variety of special programs in the community that must be provided for our retarded citizens represents an enormous outlay as well. The costs in terms of human suffering and in lost human resources and potential are beyond mathematical calculation. We must remember that mental retardation and the other developmental disabilities, if uncorrected, persist over a life time and that many thousands of babies will be born in this decade who will never have a chance, for even part of their lives, to share in the ordinary opportunities and challenges that we here enjoy. More than that, they will be denied the opportunity to contribute to the commonly shared goals and aspirations of our society.

Despite the enormous complexities that attend the problem of mental retardation, over the past two decades we have made enormous scientific progress toward the twin goals of prevention and amelioration of mental retardation. Much of this knowledge has been put into practice with outstanding results. For example, we now understand the biochemistry underlying some specific genetic disorders and through proper intervention we are now able to create medical and environmental conditions where these people, who only two decades ago would have been profoundly retarded, are able to live normal lives. Studies of learning process have enabled us to develop effective educationally-based procedures that ameliorate many of the learning and behavior problems associated with mental retardation. We have also learned a great deal more about causes of mental retardation, knowledge that can have enormous significant public policy implication. For instance, we now have convincing experimental and descriptive data showing that alcohol is a teratogen that can have devastating effects on the developing fetus. Public policy has followed from the empirical demonstration that environmental exposure to lead can cause a continuum of biological and behavioral risks ranging from very severe to mild in form.

Over the past few years a variety of exciting new behavioral and biomedical concepts and techniques have been incorporated into the study of mental retardation, such as the role of peptides and neurotransmitters in the functioning of the nervous system, sophisticated quantitative techniques for the study of neuropathology and neuroanatomy, the introduction of new cytogenetic procedures, the discovery of new methods for analysis of plasticity of behavioral development, and new methods for promoting generalized learning and transfer of skills.

These are but a few examples of research-derived technology that has enabled us to understand part of the complex nature of mental retardation and to improve ultimately the lives of many of our citizens while greatly reducing costs to society. Without the continuing support provided by Congress these accomplishments would not have been possible.

Yet, since 1974 the commitment to mental retardation research has deteriorated and if this trend continues the effects will be extremely serious. Dr. Berkson and I have, over the past several years, conducted various types of analyses of NICHD funding patterns with particular reference to the status of mental retardation as a funding priority within NICHD. The one general and compelling conclusion emerging from these analyses is that mental retardation research, both in absolute and relative terms, is in a much less favorable position today as compared with its status ten years ago. Since 1974, for example, the overall decline in mental retardation research support, expressed as a proportion of the total budget of the Center for Research on Mothers and Children, is almost 20%. In 1983 dollars our research capability is about half of what it was in 1974. Core support funding for the 12 national Mental Retardation Research Centers has been severely affected. New programs and new centers, inaugurated without additional appropriations, must inevitably be funded to the detriment of existing programs. Attached is a graph that shows a regular and continuing decline in support for mental retardation research, from 1972 to 1982.

In 1982, 33 NICHD grants directly relating to mental retardation were approved through peer review with excellent priority scores of 243 or better, but could not be funded owing to lack of money. Ten years ago most of these grants would have been funded. These proposals cover a wide range of extremely important biomedical and behavioral problems including, for example, a number of highly significant projects on Down syndrome and developmental neurobiology. The total amount of money requested for these projects came to $2,397,000. The scientific knowledge lost because these high quality projects could not be undertaken is tragic, for it is only through scientific inquiry of this nature that the mysteries of mental retardation will be unraveled.

Expenditures for research related to mental retardation have declined steadily both in relation to inflation and as a proportion of the relevant program within NICHD. Therefore, our first major purpose is to assure continued support for mental retardation research and to reverse the decline in funding.

We respectfully encourage Congress to increase appropriations to the NICHD to a level that, at the minimum, ensures the continuity of research and research training programs and at a level that begins to reduce the decline in funding for mental retardation research about which we spoke earlier. We believe that this can be done in two ways: (1) provide for an increment in the NICHD budget adequate to offset the effects of inflation and to accelerate the effort in mental retardation research and, (2) more specifically, provide for meaningful increment in core support for the national Mental Retardation Centers.

Our second purpose is to suggest foci of the narrative report language. We believe that improvement of mental retardation services depends on excellent basic behavioral and biological research in the areas of prevention, early diagnosis and intervention, learning, and long-term care. Most important, because mental retardation is a constellation of behavioral phenomena with numerous biological and psychosocial causes, collaborative research programs incorporating behavioral and biological components should be fostered. With these considerations in mind we respectfully make the following specific recommendations:

1. We urge the Congress to increase funding by 10% to the NICHD from $254,000,000 in the current fiscal year to $279,000,000 in fiscal year 1984. This is in contrast to the Administration request for $257,000,000 for fiscal year 1984.

2. That the Mental Retardation Research Centers be designated as a special item in the budget and that $8,000,000 be appropriated for core support for these centers.

3. That report language indicate that $2,500,000 of the increase be designated for support of regular research grants of high quality in the general area of mental retardation.

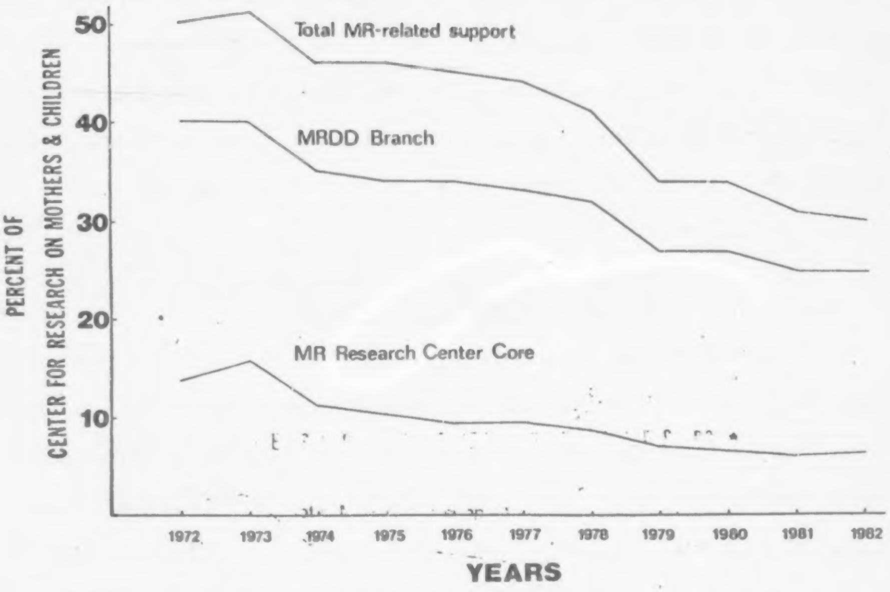
4. That report language indicate congressional intent for half of the increase, or $12,500,000, to be directed for research in the area of developmental neurobiology.

5. That the Congress express its commitment to the continuation of high quality predoctoral and postdoctoral research training.

I should like to close with a quote from Dr. Nicholas Hobbs, who died recently, but who devoted his own remarkable life and considerable talent to the belief that human decency can be most fully expressed in our attitudes toward children. In the dedication of his last book entitled the Troubled and Troubling Child he wrote:

> "To the children of our nation whose
> hope lies in our caring and whose
> futures are our trust."

TRENDS IN SUPPORT OF MENTAL RETARDATION RESEARCH*



* THESE CURVES DERIVED FROM DATA SUPPLIED BY NICHD

STATEMENT OF DAVID CHADWICK, M.D., MEDICAL DIRECTOR, CHILDREN'S HOSPITAL AND HEALTH CENTER OF SAN DIEGO, CALIF.

Introduction

I am Dr. David Chadwick, Medical Director of Children's Hospital and Health Center (CHHC) in San Diego, California. CHHC is a 158-bed tertiary care pediatric center serving two million people in San Diego and Imperial Counties.

The Center has many special programs, including a hospital-based child protection program and one of the largest speech, hearing and neurosensory centers on the West Coast. CHHC also conducts a substantial amount of research in many aspects of children's health, including studies on the development of walking in preterm infants, electric response audiometry in infants and children, cognitive dysfunction in autism and the outcome of preschool impairment in language development.

NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT

From the perspective of promoting quality child health care and research on childhood diseases and disabilities, CHHC takes this opportunity to comment on the Administration's proposed Fiscal Year (FY) 1984 budget for the National Institute of Child Health and Human Development (NICHHD). CHHC enthusiastically supports the research undertaken by the NICHHD to improve the health and well-being of the developing infant and child and to prevent conditions which have their origins early in life and lead to adult disabilities and early death. Today's study of problems associated with reproduction and development, such as birth defects, premature birth and mental retardation, may be the key to preventing tomorrow's lifelong disabilities and early death suffered by thousands of individuals. For example, mental retardation resulting from one genetically determined defect -- phenylketonuria (PKU) --

nearly has been eradicated with the development of an inexpensive screening test and an effective dietary treatment. Similarly, a screening test for hypothyroidism -- another inborn error of metabolism resulting in severe mental retardation -- also has been developed and is coming into widespread use. Additionally, hypothyroidism now can be diagnosed at birth and an easy and effective treatment can be applied immediately. Clearly, the work carried on by the NICHHD is of major significance in preventing costly health problems in the future.

CHHC also recognizes the capable leadership demonstrated by the Institute's Director, Mortimer B. Lipsett, M.D., during the past year. Dr. Lipsett outlined in testimony before this Subcommittee many of the issues under study at the Institute, including: (1) the development of animal models for in utero medical and surgical treatment of fetal defects; (2) the successful development of an animal model for in utero treatment of fetal growth retardation; (3) the application of new computer technology to measure the visual and auditory capabilities of very young infants; (4) the development of a synthetic hormone to provide treatment for children with growth hormone deficiency; and (5) developments in treating male and female infertility through the use of a luteinizing hormone-releasing hormone (LHRH). These examples are a few of the many advances being pursued by the NICHHD.

Recognizing that the National Institutes of Health cannot enjoy unfettered expansion during a period of economic austerity, CHHC nevertheless is concerned over the pattern of fiscal constraint shown in the decreasing numbers of research and training grants funded by the NICHHD. For example, under the FY 1981 appropriations level of $220,628,000, a total of 1,249 research grants were funded with 453 representing new, competing grants. Also, 571 training grants were funded in that year. In contrast, under the FY 1982 appropriations level of $226,309,000, only 1,236 research grants were funded with 439 representing new, competing grants. Also, 626 training grants were funded in that year. Under the FY 1983 appropriations level of $253,655,000, a total of 1,254 research grants will be funded with only 364 representing new, competing grants. Also, only 570 training grants will be funded during FY 1983.

For FY 1984, the Administration is proposing a budget of $256,592,000 -- a mere 1.1 percent increase over the FY 1983 level. The Institute has projected that 1,278 research grants will be funded with 437 representing new, competing grants. Also, 554 training grants will be awarded during the upcoming fiscal year. Compared to FY 1981, the number of competitive grants to be funded in FY 1984 will drop by approximately four percent and the the number of training grants will decrease by nearly three percent. Moreover, the Department has factored into each award a ten percent reduction for reimbursement of indirect costs.

This steady decline in the number of research and training grants to be funded by the NICHHD cannot continue without having an adverse impact on the rate of growth of scientific knowledge and its application in terms of treatment and preventive medicine. Medical institutions, like children's hospitals, which rely on federal funding of research projects will have fewer resources available to finance new initiatives. Additionally, fewer M.D.'s and Ph.D.'s will be encouraged to enter research careers as funding for their endeavors steadily diminishes. Moreover, as progressively fewer new research and training grants are funded, the momentum in diagnosing, treating and preventing congenital and hereditary diseases will be lost.

CHHC urges this Subcommittee to continue its steadfast support of the Institute's work in recognizing, treating and preventing childhood disabilities and diseases. In this respect, we request this Subcommittee to provide $284 million for the NICHHD in FY 1984.

CHILD ABUSE PREVENTION AND TREATMENT ACT, AS AMENDED

I also would like to take this opportunity to comment on the funding provided the Child Abuse Prevention and Treatment Act (Public Law 93-247), as amended. My testimony arises from two different perspectives. First, as head of the child protection program and as an active member of the physical abuse review committee at CHHC, I treat scores of abused children every year. Second, as one of two consultants to the American Academy of Pediatrics on child abuse problems and as a frequent witness in civil and criminal proceedings, I can attest to the profound impact which child abuse plays in shaping the formative years of vast numbers of this nation's young people.

Since enactment of the Act in 1974, we have made significant progress in both knowledge and treatment of child abuse. The National Center on Child Abuse and Neglect (NCCAN) is to be commended for its major role in heightening our awareness of this problem through its research on the issue and its guidance to state and local agencies in combating the problem. NCCAN currently funds 65 vital research and demonstration projects nationwide which encompass a variety of activities. The major areas involve: prevention; clinical treatment; public child protection services; legal juvenile court services; sexual abuse prevention; adolescent maltreatment (including sexual exploitation) and prevention; protection of children in special institutions; mental health programs for abused children; and programs aimed at children with developmental and other disabilities. However, budget reductions, in the face of increased instances of child abuse nationwide, threaten NCCAN's progress in these areas.

Budget Overview

In 1981, the Administration proposed that the programs authorized by Public Law 93-247, as amended, should be enfolded into the Social Services Block Grant in FY 1982. While Congress rejected the Administration's proposal, funding for the programs was cut from the FY 1981 level of $22.9 million to $16.2 million. Specifically, $9,479,000 was appropriated for the discretionary funds program and $6,720,000 was appropriated for the state grant program.

In 1982, the Administration again proposed a substantial reorganization of the child abuse prevention and treatment programs for FY 1983. Funds for the state grant program were to be reduced by $2 million and the discretionary funds for research and demonstration activities were to be grouped with other Office of Human Development Services (OHDS) projects under a single level of funding at $31 million. This latter proposal provided for no increase in funds over the FY 1982 level. Congress again rejected the Administration's proposal and agreed to fund these programs at the FY 1982 appropriation level.

This year, the Administration is proposing to continue funding for the state grant program at $6,720,000 for FY 1984. However, for the discretionary funds program, the Administration is proposing to block grant funding allocated for child welfare research, child abuse prevention and treatment projects, social services research and adoption opportunities at $9 million. Compared with the FY 1983 levels of funding ($22 million) for all of these programs, this figure represents a catastrophic budget reduction.

Consequences of Budget Reductions

Since implementation of these budget reductions, states across the country have reported increased instances of child abuse. A survey of child abuse specialists in all fifty states and the District of Columbia, conducted in the fall of 1982 by the National Committee for the Prevention of Child Abuse, revealed that 39 states witnessed an increase in reported cases of abuse in the past year. Moreover, fourteen states recorded an increase in the number of deaths due to abuse and 33 states reported more serious cases of abuse.

For the State of California, a fifty percent increase in physical abuse cases and a 95 percent increase in sexual abuse cases were seen from 1979 through 1981. During this same time period, San Diego County witnessed astronomical increases in the reported cases of physical abuse (271.82%) and sexual abuse (467.08%). In Imperial County, substantial increases also were recorded during this time frame for physical abuse (16.06%) and sexual abuse (92.86%).

At the San Diego Children's Hospital, the numbers of child abuse deaths have risen since 1979. In 1979, CHHC was credited with no child abuse deaths. However, in 1980, four deaths were recorded; in 1981, six deaths; and in 1982, another six deaths were reported.

Indications from local authorities reveal that these soaring rates of increase have continued unabated throughout the past year. To a degree, these increased reports of child abuse reflect our heightened awareness and recognition of the problem itself. In the State of California, more stringent reporting requirements as well as severe economic pressures on families also have been cited by officials as contributing to the marked rise in child abuse cases.

Yet, at a time when child abuse appears to have reached epidemic proportions, the State of California has been forced to reduce by approximately twenty percent the number of budgeted social work positions to administer child protection services. This reduction has occurred as a result of federal cutbacks in funds for child abuse prevention programs since 1981. In turn, this reduction in the work force has raised the case load per social worker.

Because of these circumstances, every county in the State has been forced to limit the type of cases handled by their child protection agencies. For example, several counties have implemented policies not to treat children above the age of twelve years except in rare circumstances. Other counties are considering more stringent limitations such that children above the age of six years will not be treated. As a result of these restrictions, a child above a certain age limit with superficial injuries -- *e.g.*, slight bruising, welts or scars -- will not be admitted for treatment. Only children with more severe injuries -- *e.g.*, black eyes or burns -- will be handled by the child protection agencies. Clearly, as a result of budgetary constraints at a time of record increases in reported child abuse cases, the State of California has been forced to provide primarily crisis intervention rather than preventive and supportive services.

Conclusion

Despite the increase in public awareness of this national problem, more work clearly needs to be done in the areas of child abuse prevention. The very success of NCCAN's programs has led us to realize that abuse and neglect of children is a serious, and unfortunately growing, problem in America today. Recent studies have confirmed that each year over one million children are needless victims of abuse and neglect. Over 44,000 children are the victims of sexual abuse. At least

1,000 children die annually as a result of severe physical abuse and neglect. These estimates are based only on cases which actually have been reported. Most experts agree that the real incidence of abuse is two to three times higher.

The National Center on Child Abuse and Neglect stands as a model federal initiative: it was created to address an acute national problem; it has served as a resource for state child abuse programs; and it has joined successfully with the private sector to address the many problems associated with child abuse and neglect.

If we are going to continue to have an impact on the problem of child abuse in the United States, it is critical that the federal presence be maintained and that the activities of NCCAN and the programs it administers be given sufficient financial support. Any cutback in federal funds, particularly at this time, will have a devastating effect on our ability to combat this serious national problem. In fact, if additional funds are not authorized under the Act, an already severe national problem will continue to deteriorate without any hope of improvement in the near future.

For these reasons, we urge this Subcommittee to reject the President's FY 1984 Budget Request and to substitute the FY 1981 funding level of $30 million for the child abuse prevention programs.

SUBCOMMITTEE RECESS

Senator PROXMIRE. The subcommittee will stand in recess until tomorrow morning at 8:40, when we will convene in this room to continue our public witnesses hearing on the budget for the National Institutes of Health.

[Whereupon, at 11 a.m., Wednesday, April 27, the subcommittee was recessed, to reconvene at 8:40 a.m., Thursday, April 27.]

DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 1984

THURSDAY, APRIL 28, 1983

U.S. SENATE,
SUBCOMMITTEE OF THE COMMITTEE ON APPROPRIATIONS,
Washington, D.C.

The subcommittee met at 8:30 a.m., in room SD–116, Dirksen Senate Office Building, Hon. Lowell P. Weicker, Jr. (chairman) presiding.

Present: Senators Weicker, Andrews, and Proxmire.

NONDEPARTMENTAL WITNESSES

Senator WEICKER. The subcommittee will come to order.

Today we'll continue our public witness hearings on the fiscal year 1984 budgets for the National Institutes of Health. As you can see, we're going to be using this system of timing lights. The reason for it is that we have so many witnesses to accommodate I want to make sure that everybody has a chance to submit their statement for the record, and has a few moments to explain the comments in that statement.

And I hope all witnesses will save me the embarrassment of using the gavel, and that's why I try to do it quietly with lights but believe me the intent is the same: when the red light goes on, I would appreciate it if you would bring an end to the testimony so as to accommodate others.

Our first witness today is Dr. John Tew, the president of the Congress of Neurological Surgeons. Dr. Tew was unable to appear at his originally scheduled time and we're happy to have him with us this morning instead.

I understand Dr. Tew will be discussing the 1984 appropriations for the National Institute of Neurological and Communicative Disorders and Stroke.

STATEMENT OF JOHN M. TEW, JR., M.D., PRESIDENT, CONGRESS OF NEUROLOGICAL SURGEONS

Dr. TEW. Thank you.

I have with me also Dr. James Tewell, a professor of neurology, Bowman Gray School of Medicine, who represents the World Federation of Neurology and the Research Center Stroke Directors.

Stroke is the primary neurological problem in the United States. It's the major cause of disability and the third leading cause of death in our country. Deaths each year account for one-third of the 500,000 individuals attacked by stroke. There are nearly 2 million people disabled by stroke each year, and the economic cost accounts for more than $8 billion per year.

Significant progress has been made toward the prevention of stroke through the identification and treatment of risk factors: principally small stroke and blood pressure problems. Nevertheless, one quarter of the people who suffer a stroke each year are young individuals.

Cerebrovascular research centers and universities throughout the country have contributed greatly toward the understanding of stroke. These centers, funded by the NINCDS, concentrate on major research problems of stroke diagnosis and treatment. They serve as an invaluable resource for training of young individuals, physicians and scientists interested in stroke, and serve as a focal point for transfer of technology.

The momentum of stroke research built up over the past 20 years is being lost. A new national program which establishes a regional network of stroke research and training centers must take direct advantage of the opportunity to develop and disseminate the knowledge needed to combat this dreaded problem of stroke. An appropriation of an additional $25 million to add to the existing $16 million appropriated and used by NINCDS to fund stroke research is a matter of national priority.

For fiscal 1983, only 3.9 percent of all applications submitted to the National Institute of Neurological and Communicative Disorders and Stroke were in the area of stroke. In 1982 funding for research in the field of stroke was $1.9 million from the National Heart, Lung, and Blood Institute and only $16 million from NINCDS, less than 4 percent of the annual budget. That the third leading cause of death in this country and the major leading cause of disability is funded at less than the cost of one small jet aircraft is an appalling fact.

Can the forces that have led to this deplorable state be reversed? We think not, unless a sociopolitical process can be mobilized to appropriate the targeted funds for more centers of excellence in stroke research and treatment. The center concept is essential to serve as a focal point for the development of seasoned and established investigators and clinicians who will serve as role models for young investigators.

The center concept stabilizes personnel, attracts people from diverse interests, from many disciplines. More important, the stroke center concept will provide stability, and eliminate the 3-year cycle of individual grant review which saps time and effort from productive research activity.

In conclusion, a rapid and dramatic infusion of funds, $25 million to add to the existing $16 million funded for stroke research—which amounts to less than 20 cents per citizen per year—is essential to fund the necessary stroke centers mandatory to attract and support the young investigators needed for basic and clinical research and stroke in this country.

Thank you, sir.

Senator WEICKER. Thank you very much.

What was the 1983 level of funding here?

Dr. TEW. $16 million from NINCDS and $1.9 million from the Heart Institute.

Senator WEICKER. And what is proposed for 1984?

Dr. TEW. There's no designated amount but according to the present statistics, approximately the same amount would be funded.

Senator WEICKER. And it's your position that at least an additional $25 million is necessary?

Dr. TEW. Yes, sir, to be specifically designated for stroke centers. The majority of funding now is in the R–O1 or individual grant project which goes principally to Ph. D's, rather than to clinical investigators, and those have to be reviewed on a 3-year basis.

PREPARED STATEMENT

Senator WEICKER. Thank you very much, I appreciate it.

[The statement follows:]

STATEMENT OF JOHN M. TEW, JR., M.D.

The cerebrovascular diseases including stroke are the primary neurological problem in the United States. They are a major cause of permanent disability and the third leading cause of death. Deaths each year from strokes occur in about 170,000 of an estimated 400,000 attacks. There are about 1.9 million disabled stroke survivors in the United States and the economic costs of these disabilities are estimated to be over $8 billion per year.

Significant progress has been made toward the prevention of stroke through the identification of predisposing risk factors such as transient ischemic attacks ("small strokes") and high blood pressure. The death rate has declined from 102.1/100,000 in 1973 to 76.9/100,000 in 1979. Nonetheless, there remain large numbers of patients who do suffer a stroke and for whom aggressive therapy is required.

Cerebrovascular clinical research centers in university medical complexes across the country have contributed greatly to our understanding of stroke. These centers, funded by the National Institute of Neurological and Communicative Disorders and Stroke, concentrate on the major research problems of stroke diagnosis and prevention. They are also an extremely valuable resource for the training of young physicians and scientists interested in stroke and as a focal point for technology transfer.

If the momentum of stroke research built up over the past 10 to 20 years is to be maintained, it is necessary that we be able to capitalize on the many promising research leads now being evaluated. A national program which establishes a REGIONAL NETWORK OF STROKE RESEARCH AND TRAINING CENTERS would take direct advantage of the opportunities presently available to develop and disseminate the knowledge needed to decrease both the occurrence of stroke and to diminish its consequences on the quality of life of those who survive this threat to the brain. We estimate that an appropriation to the NINCDS of an additional $25 million for stroke research will accomplish this purpose of high national priority.

Federal funding of research in stroke has been awarded through three principle mechanisms.

1. Center programs which incorporate a multidisciplinary approach.

2. Individual research grant projects.
3. Contracts with clearly defined goals and timetables set and supervised by the awarding federal agency.

There is no decisive evidence concerning the appropriate mix of investment of research funds. However, it is remarkably clear that there has been an alarming decrease in the number of applications designated to the broad field of stroke research. For fiscal year 1983, only 3.9 percent of all applications submitted to the National Institute of Neurological and Communicative Disorders and Stroke (NINCDS) were in the area of stroke. On the other hand, the percentage of applications actually approved and funded increased considerably in comparison to other categories of biomedical research funded by NINCDS. Sixty-seven percent of grants were approved and sixty-three percent were actually paid based on a mean priority score of 175 while the actual pay line was 165. In 1982, funding for research in the field of stroke was 1.9 million dollars from the National Heart, Lung and Blood Institute and 25 million dollars from the NINCDS, the later represents less than four percent of the annual budget. That the third leading cause of death in this country is funded less than the cost of one small jet aircraft is a rather appalling fact. Furthermore, there is ample evidence that private fund raising organizations do not provide equitable support and publicity for the field of stroke to condition public awareness of the problem.

Can the forces that have led to this deplorable state be reversed? I think not, unless a sociopolitical process can be mobilized to influence the United States Congress to designate targeted funds for centers of excellence in stroke research and treatment. The center concept is essential to serve as a focal point for development of seasoned and established investigators and clinicians who will serve as role models for young students and investigators. A center should become a stimulus for satellite research and provide a halo effect and discretionary funds for beginners to initiate investigative careers. The center concept stabilizes personnel, attracts people of diverse interests from many disciplines and gives them an opportunity to work together. Conversely, individual project grants tend to isolate basic scientists and discourage clinical investigators. Development of center grants will encourage clinical research which has progressively decreased because of the highly competitive review process and increasing requirement for commitment to patient care in medical centers. Center funding will encourage the Ph.D. investigator to join or collaborate with clinical departments and facilitate a track for academic advancement. Establishment of Center Grants for Stroke will encourage the young clinician and scientist to consider an academic career and insure funding for small project grants. Perhaps more important, Center Grant Funding can provide stability, eliminate the three year cycle of individual grant review which saps time and effort from productive research activity and encourages premature and at times fallacious reporting.

In conclusion, a rapid and dramatic infusion of funds for the establishment of a critical number of Stroke Centers is mandatory to attract and support the young investigators needed for basic and clinical research and stroke.

It is our opinion that these funds can be generated only if sufficient public awareness is aroused to bring this critical matter to the attention of the Appropriations Committees of the United States Congress. Direct appeals to the appropriate individuals by public-spirited and concerned constituents must be organized.

Our goals should be to obtain appropriation of designated funds for Stroke Centers to be added to the annual NINCDS budget. The Center grants should be awarded on a long-term assignment by the peer review site visit mechanism. In order to encourage development of new centers of excellence where established expertise is not currently available, the existing priority scoring mechanism for funding of individual grant proposals should not be suspended and special consideration for program relevance established. A special study section should be established to award and review the center grant projects.

Attached to this position paper is a report of the National Advisory Council of Neurological, Communicative Disorders and Stroke Subcommittee on Clinical Investigation. This report concluded that emphasis on the continuum of research training experience beginning with the process of selection for medical school entrance, provision of opportunities for research experience in undergraduate education and an environment in postdoctoral training which considers research important and socially useful is most likely to provide the answer for the continuing decline in physician investigators which was eluded to in the position paper. The subcommittee recommended:

1. Greater use of training grant awards to expose medical students to research. Active promotion of program applications for research from institutions with strong postdoctoral training programs.
2. Inclusion of research training for at least one or two years in residency programs. Continuing appointment of physician applicants to trainee positions and institutional training awards in both basic and clinical research.
3. Emphasis on the teacher investigator development award and its active promotion by the NINCDS in collaboration with professional and lay groups.
4. Encouragement of continual sustenance of a joint M.D./Ph.D. training program as a source of clinical investigators.
5. Development of improved communication and collaboration between the biomedical research training activities of professional societies, national health voluntary organizations and the NINCDS.

STATEMENT OF BARBARA H. LAYMAN, PRESIDENT, ASTHMA AND ALLERGY FOUNDATION OF AMERICA

Senator WEICKER. The next witness is Barbara Layman, national president of the Asthma and Allergy Foundation of America, accompanied by Dr. Philip Norman, the past president of the American Academy of Allergy and Immunology.

Please proceed.

Ms. LAYMAN. Good morning, Mr. Chairman. I am Barbara Layman from Waynesboro, Pa., and I'm the national president of the Asthma and Allergy Foundation of America. Our organization spearheads the movement to combat these widespread immunologic diseases.

We have submitted to your staff our written testimony and request that it be included in the record.

With me is Dr. Philip Norman from Baltimore. Dr. Norman is the past president of the American Academy of Allergy and Immunology. Our two organizations are partners in a crusade that has immense significance for the future health of millions of Americans.

In just a moment Dr. Norman will briefly present to you our recommendations for the fiscal year 1984 budget appropriations for the National Institutes of Health in general, and the National Institute of Allergy and Infectious Diseases, in particular.

Before he does, however, I wish to tell you something about the suffering and the consequences of these illnesses: An enormous number of children and adults, over 35 million, are handicapped by asthma and allergy.

My oldest daughter, Linda, has experienced the fright and miseries of these chronic afflictions since she was 9 months old. The nighttime dashes to the hospital emergency room, frantic injections of adrenaline at home to halt violent and life-threatening attacks have always been the sudden reactions to totally unexpected irritants that continue to destroy her most carefully laid plans.

I can still smile a little because my Linda is still alive and coping, yet her future remains a big question for her and for us.

I know, Mr. Chairman, that others who have appeared before this subcommittee are unable to point to a loved one who is still alive.

But as lucky as we are to still have Linda, up to 5,000 children and adults are much less fortunate, for that's the number of Americans who die each year from asthma alone.

I often refer to asthma and allergic diseases as closet illnesses, for they are often dismissed, hidden from view, and stigmatized. That is not true. One way to count these health problems is to consider that the $4 billion our patients and their families pay each year directly and indirectly to treat these diseases is almost equivalent to the entire NIH budget.

We are well aware, Mr. Chairman, that we come before you during a time of difficult questions about the true cost and benefit that we are receiving from our Government's efforts in many social and economic areas, and we know of the national debates over our defense. Yet, Mr.

Chairman, we believe that your subcommittee's report of a continuing and very vigorous biomedical research program is a strong vote for this Nation's most important defense, our immune system defense against diseases and death.

Thank you.

And I now wish to ask Dr. Norman to present our recommendations.

Senator WEICKER. Dr. Norman.

Dr. NORMAN. Due to the constraints of time, I'll be brief.

We believe that the total NIH needs an increase of 12 percent over last year of $487 million. Specifically in the areas that we are interested in, we think NIAID research centers should have their funding increased to $7 million above the President's budget. These centers are vitally important to fund basic and clinical research in important disease areas.

We think there's a need for trial immunotherapy of adult asthma, it's much needed and we hope the committee pays close attention to moneys for clinical trials in general.

We believe there is a need for 50 additional research career development awards in order to develop the young people who are so essential to carrying on the research that Ms. Layman requests.

We believe there's an additional need for training at the pre- and post-doctoral level for allergists and clinical immunologists. There's a woeful lack of such people.

And finally, we believe that there is a need to appropriate funds for an overall NIH immunology research initiative. The basic science of immunology impacts not only on asthma and allergic diseases, but cancer, diabetes in children, rheumatoid arthritic, cystic fibrosis, multiple sclerosis, and the new disease, acquired immune deficiency syndrome.

The National Institute of Allergy and Infectious Diseases is in the best position to spearhead a coordinated initiative throughout the National Institutes of Health.

Thank you very much for your time.

PREPARED STATEMENT

Senator WEICKER. Dr. Norman, thank you, and Ms. Layman, thank you, and I can assure you the committee will give great attention to your requests.

[The statement follows:]

STATEMENT OF BARBARA H. LAYMAN

Mr. Chairman. My name is Barbara Layman. I am the mother of a severely allergic child. I am also President of the Asthma & Allergy Foundation of America, a non-profit organization dedicated to the cure, control, and eventual prevention of these diseases, while improving the quality of life of the 35 million men, women and children who currently suffer from them. The Foundation has numerous chapters throughout the country. All of them are fueled by volunteers, as well as by patients and parents, who work hard to overcome asthma and allergies while helping others do the same.

With me is Dr. Raymond G. Slavin. Dr. Slavin is President of the American Academy of Allergy and Immunology. The Academy is the nation's largest professional society of scientists and practitioners in these fields, with a membership of over 3,000 here in the United States and in 41 countries abroad.

Both the Foundation and Academy are working hard toward one common goal: the eradication of asthma and allergic diseases. These diseases are among the nation's most common, costly, and misunderstood health problems. They afflict at least 35 million Americans: approximately one out of every six Americans suffers from at least one of these disorders. Conservative estimates indicate 9 million Americans suffer from asthma, with or without hay fever; another 15 million have hay fever alone or allergic reactions to foods, drugs, or insect stings. More than 6 million of these sufferers are children who have at least one allergic disease, and many have more than one.

High as these figures are, they reflect only the number of people who currently suffer form asthma and allergies. They do not record those who have had reactions in the past, but have since "recovered." For example, of all Americans living today, about 15 million have had, have or will have asthmatic episodes.

Americans suffering from asthma and allergic diseases spend in excess of $2 billion each year for physicians' services, drugs, and hospital and nursing home care. While severe allergic reactions can cause death, most allergic illnesses are of a chronic nature that leads to restricted activity and loss of work and school time. America's asthma sufferers spend a total of 35 million days in bed each year because of the disease. The indirect costs for allergies -- such as wages lost because of illness -- are more difficult to calculate, but they exceed $800 million a year for asthma and hay fever alone.

Research is our only hope for the effective control of these diseases and, hopefully, their prevention altogether. That is why, Mr. Chairman, we have brought our concerns before this Subcommittee today. We strongly believe the President's proposed budget for the National Institutes of Health (NIH) falls dangerously short of this nation's research needs, and may jeopardize the pace of scientific progress not only for asthma, allergies, and other immunologic diseases, but for all other health problems facing this country today.

NATIONAL INSTITUTES OF HEALTH

The AAFA and AAAI firmly believe the Administration's proposed budget for fiscal year 1984 is insufficient for the National Institutes of Health (NIH) to carry out their important goals. We believe the miniscule percentage increase in funding for the NIH and the National Institute of Allergy and Infectious Diseases (NIAID), in particular, will disrupt the nation's investment in investigator-initiated research. The $73 million increase in NIH funding for fiscal year 1984 does not even meet the costs of inflation, and may well halt the momentum of biomedical research in this country. We fear the proposed budget will:

- Slow down the flow of new knowledge to prevent and treat disease;
- Abort promising research projects;
- Discourage innovative science;
- Dissuade bright young people from pursuing research careers; and
- Disrupt the research careers of highly talented scientists.

To preserve the vitality of the biomedical research effort, we urge this Subcommittee to increase the fiscal year 1984 funding for NIH by $487 million. This level of increase is backed by over 110 groups and organizations leading the biomedical research effort in this country. We feel it's the minimum amount that will permit current initiatives to continue in the areas of research, training, clinical trials, and equipment. Our recommended funding level for NIH represents an approximate increase of 12% as opposed to the 1.8% increase in the President's proposed budget. This comes at a time when the research and development grants for the Department of Transportation are increased by 27%, for the Department of Defense by 29%, for the National Science Foundation by 18%, and for the Alcohol, Drug Abuse and Mental Health Administration by 15%. Essentially, this 12% increase would only allow NIH to fund most programs at last year's levels - a modest request at best.

Several years ago, when Congress concluded that funds should be available each year to award about five thousand grants for new projects or to complete renewals, it was the consensus of most informed observers that such support would be adequate to minimally maintain medical research in this country. NIH was able to award 5,100 grants for new and competing projects in fiscal year 1981. In fiscal year, 1982, this figure dropped to 4,740, and, in fiscal year 1983, it's projected that NIH will be able to award 4,900 grants.

That a minimum goal has become a maximum for budgetary purposes is tragic, and it should never be accepted by the biomedical research community as a satisfactory governmental response to the demands of medical research. Further, and more importantly, these numbers do not tell the true human story that is the motivating force behind medical and scientific research. People suffer from diseases. Friends, family members, acquaintances, and business associates who have debilitating or disrupting diseases are not the only victims of these conditions -- they touch all who live and work with them. If the Administration prevents the research efforts of NIH from even keeping pace with the rate of inflation, this will display a lack of understanding of, and compassion for, the actual human costs of disease. One can cite figures indicating that for each dollar invested in research there are $13 in savings from benefits, such as reduced incidence of illness, medical costs, and increased life expectancy. But this, too, falls into the trap of looking at biomedical research purely in economic terms. The point is simple -- without energetic and stable medical research, we will lose ground in this nation's pronounced crusade against disease. The Administration's budget falls far short of displaying a true commitment to this effort.

National Institute of Allergy and Infectious Diseases

Since the National Institute of Allergy and Infectious diseases (NIAID) deals with allergy, asthma, and immunology, both AAFA and AAAI are extremely interested in NIAID's ability to achieve its goals. Unusual opportunities now exist for the development of new and improved methods for the prevention and treatment of asthma and other allergic diseases. These diseases are almost exclusively problems of the immune system.

By using new techniques, such as cell cloning, recombinant DNA technology, and monoclonal antibodies produced by hybridomas, and by manipulating the regulatory aspects of the immune system, scientists see great potential for making major improvements in health during the next decade. The strategy for taking full advantage of these opportunities includes: (1) basic research on the immunological and chemical mechanisms that are responsible for asthma and allergic reactions, (2) basic and clinical research on improved immunotherapy for the treatment of specific allergies, and (3) development of new drugs to combat the destructive inflammation that occurs in the tissues affected by allergic reactions.

To take advantage of these exciting research advances, we request that the Subcommittee seriously consider the following recommendations.

- NIAID-Supported Research Centers - **We emphatically urge that the Subcommittee, through report language and appropriations, mandate the NIAID centers program. An increase of approximately $7 million above the President's budget is required to support 28 centers and provide for adequate funding of research and technology transfer activities.**

The work of NIAID has benefitted enormously from the use of interdisciplinary centers which apply both basic and clinical research to important disease areas. Asthma and Allergic Disease Centers encourage close coordination between research scientists and clinical investigators, and integrate the basic concepts of immunology, genetics, biochemistry, and pharmacology into clinical investigations. These centers foster a better understanding of the complex problems underlying asthma and allergies. Similarly, Centers for Interdisciplinary Research on Immunologic Diseases have accelerated the clinical application of new knowledge of the immune system. These centers stimulate discovery in clinical and fundamental immunology and allergy, bringing to light the results of these new discoveries to patients and physicians. Having made tremendous strides in translating research into practice, the NIAID research centers warrant your full support.

- **Clinical Trials - We strongly urge the Subcommittee to appropriate sufficient funds for a much needed trial on Immunotherapy of Adult Asthma. This trial would determine the efficacy of immunotherapy in asthma management using five standardized allergenic reagents. It is estimated that the trial will take six years at a cost of $1 million per year. This is a mere pittance, however, when one considers that asthma ranks among the leading causes of physician visits and that more than $400 million are paid each year just for disability benefits.**

The Subcommittee should pay close attention to the monies available for clinical trials in general; they are usually prerequisites for translating the results of research into normal medical practice to diagnose, treat or prevent disease. There is almost always a lag time of several years before the results of clinical trials are known. For this reason, these trials require a firm commitment of funds for their duration. If these trials, in whole or in part, are abandoned or cut back through inadequate federal funding, there will undoubtedly be a reduction in the application of research results to the benefit of the American people.

- **Research Career Development Awards - We strongly recommend that the Subcommittee appropriate sufficient funds to support an additional 50 awards, which would require an approximate $2 million increase above the President's budget.**

These awards are constantly neglected in spite of their critical importance to strengthen the medical school faculties in basic and clinical studies of direct importance to NIAID's mission. Whenever the total budget is reduced, this budget category bears disproportionate reductions.

This problem has very serious implications for the future of allergy research since it is apparent that investigators are making career decisions based on the availability of dollars in a given area. Obviously, the serious lack of funds for this purpose in allergy and immunology serves as an impediment, and in fact, hinders the future of research in these areas of critical importance to us.

- **Training - We encourage the Subcommittee to provide additional support for training to increase the cadre of allergists and clinical immunologists. More are drastically needed. Very few medical schools have asthma and allergy departments. Based on a 1980 survey of 124 U.S. medical schools, 69 chairmen of internal medicine departments (52%) and 52 chairmen of pediatric departments (42%) indicated a tremendous need for allergists and clinical immunologists. Thirty-five of the medical schools surveyed (28%) had no full time pediatric faculty in either allergy or clinical immunology. Thirty of the medical schools surveyed (24%) had no full time internal medicine faculty in either allergy or clinical immunology.**

It's vital that the federal commitment to biomedical research serve as an incentive for talented new scientists and clinicians to bring to the field new ideas, new approaches, and new enthusiasm. The appearance of instability in the federal commitment to research has often dissuaded young physicans from applying for research training or research fellowships. The Administration's proposed budget of fiscal 1984 is sending the wrong message to potential applicants for research training in NIH disciplines. The funds in the proposed budget set aside for research training are grossly inadequate in light of the tasks at hand. If the Administration's funding levels are enacted, there can be little doubt that the quantity and quality of research will steadily decline. Moreover, the number of trainees will fall far short of the minimum goal of 10,000 new trainees per year (for all of NIH), the level set by Congress several years ago. We urge the Subcommittee to address this issue, and provide the requisite funding for NIH in general and for the research training awards in particular. This is especially vital for NIAID, which is producing only one-third the number of new investigators each year to maintain the current levels of research.

- **Trans NIH-Immunology Research Initiative - We strongly urge the Subcommittee to direct the NIAID, through report language, to spearhead an initiative focused at coordinating the efforts of all NIH institutes relative to immunologic research. This is a rapidly developing field which impacts not only asthma and other allergic diseases but also most major health problems such as cancer, juvenile diabetes, rheumatoid arthritis, cystic fibrosis, lupus erythematosus, multiple sclerosis, and the acquired immunodeficiency syndrome. Precentage wise, NIAID is the leading source of funding for research on the immune system. Thus, it would seem appropriate for this institute to lead a coordinated initiative throughout the NIH.**

In summary, the goals, opportunities, and support requested by AAFA and AAAI will not be satisfied by a slavish obedience to the status quo. The proposed federal budget for fiscal year 1984 does not even do that, since it allows for little growth at all. To ensure that biomedical research can be carried out in the effective manner that the cause demands, Congress should fund NIH with an eye to "real growth." A provision of funding at a given percentage above the inflation rate for high priority projects will help maintain the momentum of our biomedical research effort. We urge the Subcommittee to give serious consideration to this concept. In any civilized society, commitment to the eradication of disease should be demonstrated in deed as well as in word.

Thank you, Mr. Chairman and members of the Subcommittee, for your thoughtful consideration of our recommendations. We stand ready to work with you in preserving and strengthening this nation's struggle against asthma and other allergic and immunologic diseases, as well as all diseases which afflict mankind.

STATEMENT OF ANN KONE, EXECUTIVE DIRECTOR, PAGET'S DISEASE FOUNDATION

Senator WEICKER. Next we have Ann Kone, executive director of the Paget's Disease Foundation.

Mrs. KONE. Despite what it says on my written testimony, I'm here for fiscal year 1984 appropriations for the National Institute of Arthritis, Diabetes, Digestive, and Kidney Diseases.

Senator WEICKER. Incidentally, the statements of all witnesses will be included in their entirety in the record.

Go right ahead.

Mrs. KONE. OK.

I'm here as the executive director of the Paget's Disease Foundation, representing our board of trustees, our advisory medical panel and our 16,000 to 18,000 members who believe very much in the need for the NIH programs and their continuation on a significant level.

First of all, let me explain what Paget's disease is, since very few people know about it. It's a bone disease that is often confused with arthritis; in fact, many patients have both. It affects senior citizens. What happens is that the normal bone cell replacement mechanism goes awry and the new bone cells are put down in an incorrect manner, they're weaker and the bones enlarge but become more fragile. There's bowing of limbs, particularly in the legs, causing crippling. And if the disease occurs in the skull, quite often a patient won't ever be able to find a hat large enough to fit them as the bones enlarge in their head and more serious results of neurological complications can arise. Cranial nerve compression may cause loss of hearing or balance, affect the vision, eye muscles, facial muscles, swallowing, speech becomes difficult.

Many people write us who are in their seventies, eighties, and nineties, who want to function normally but can't because their bodies won't work with them.

Now we are beneficiaries of your past support of the NIH programs. As a small foundation, we could never have supported the research studies which the NIH has, which has led to the discovery of two different drug therapies which do help this disease.

We are now members of the National Organization for Rare Disorders because of our small patient population: right now, currently being treated we estimate maybe around 200,000. But we do feel there is a potential of 2 to 3 million people out there who have Paget's and many of them should be treated.

Our primary mission as a foundation is to get the word out about these treatments, which are only about 5 years old; it's a recent discovery and one for which the NIH should be congratulated, in particular the NIADDK.

I get many letters from patients, however, one that I've quoted in our written testimony from a 58-year-old man who has had pain since 1975 and was told it was psychosomatic, checked himself into a mental hospital, and went through many tests. Finally, 4 years later he was diagnosed as having Paget's and then was not given more treatment than painkillers. So there's a great deal of education that needs to be done.

The NIADDK last year put out a wonderful pamphlet, the first brochure of its kind and we have been distributing it and gotten great, great comments from patients and doctors alike as to its benefits.

Therefore, we feel that both the research—clinical research as well as basic research programs—and the education programs of the NIADDK and the NIH should be supported in a substantial fashion.

You will be hearing later this morning more about the NIADDK coalition paper which asks for at least $475 million for the NIADDK for fiscal year 1984. We support this position.

PREPARED STATEMENT

Senator WEICKER. Thank you very, very much. I appreciate it.

[The statement follows:]

STATEMENT OF ANN KONE

Thank you for giving me the opportunity to appear before you today on behalf of the Paget's Disease Foundation. This is our first personal appearance before Congress, although we have previously sent testimony in support of funding for the NIH programs.

I am appearing in person this year because I and the Trustees and members of the Paget's Disease Foundation believe that it is vital that the levels of appropriations be adequate for the National Institute of Arthritis, Diabetes, and Digestive and Kidney Diseases (NIADDK) and the NIH as a whole. It is vital for us, because we are a very small organization, only four years old, trying to serve an affected population of approximately three million people. We need the help of the NIADDK in both its research programs and its education program.

Many of you may never have heard of Paget's disease of bone before -- in fact, that is one of the problems with the disease, it is often misdiagnosed or unrecognized. Similar to arthritis, Paget's is a crippling bone disease that affects people over 40. Normal bone cell activity changes in the disease such that excessive bone breakdown and formation results in bone that is dense but fragile. Its most common symptom is bone pain and the sensation of heat in the affected part. As the disease progresses, it causes bowing of limbs, most frequently the legs, enlargement of the skull, often so that no hat can be found that is big enough, and other neurological disturbances when the skull is involved. Cranial nerve compression may cause the loss of hearing or balance, or affect vision, eye muscles, facial muscles, swallowing, speech, and other functions. Many people in their 60's, 70's, 80's and even 90's write to us for help -- they are alert, intelligent, and wish to lead a normal life, but they are handicapped by the pain and disabling of their Paget's.

Our story is not without hope. There are on the market today two separate drug therapies which work in many cases to alleviate the patient's symptoms and retard the progress of the disease. A third drug is also helpful in difficult cases, and a fourth is awaiting approval by the FDA. These therapies have been available for only five years, although Paget's disease of bone has been known since the mid-nineteenth century.

Our primary mission as a foundation is to get word of these therapies to both the patient and the physician. We estimate that only around 200,000 patients are being treated for their Paget's today. More than three times that many should be receiving therapy. I would like to read you an excerpt from a letter we received last month from one example of these untreated victims:

"Dear Sir:

"I am a white male, age 58 who was told had Paget's Disease.

"In 1975 I developed a sharp pain in my right hip and leg. I went to a physician and told nothing was wrong as far as his exam showed. I was placed on pain medication; however, the "tooth-ache" pain did not go away.

"I was told that perhaps my pain was psychosomatic and to take hot baths and continue the pain medication. This did not seem to help and I knew the pain was real. I placed myself in a mental hospital to find the cause for the pain. While there I was told I had cancer of the prostrate and given test and a TUR. The cancer was negative. I was placed in the medical division of the hospital. I had many bone scans, etc. I was told that I had tumors in the right hip bones. I did not want anymore test, and since my condition was not mental I was released with the advice to see the Veterans Hospital Doctors.

"In July of 1979 I went to the V.A. Hospital for a exam. My records were sent from the mental hospital. I was placed on Tylenol #3 and Darvocet N-100. In September I was given a bone-scan and later told the problem was Paget's Disease. I was told by the doctor that he knew little about the disease but he would read on it. I have had several x-rays but each time told there was no change. I developed a sharp pain in the back of the neck but told this was due to damage vertebrates and had nothing to do with the Paget's. The pain in the neck still exists.

"I have been told that there is no cure for Paget's and no medication to give. Since 1979 to 1983 I have been on Darvocet and now Zomax. I receive 100 each per month. I have been as out-patient and have gone to the doctor 36 or more times, and each visit given the same medication. I have been told that it is something I have to learn to live with."

Through our foundation, this patient now has learned of the medications available to help him.

What is it, then, that we are coming to ask you for today? First of all we ask you to support the research programs of the NIADDK. It was through grants from the Institute and studies in the clinical programs that the doctors and scientists developed the therapies that we have today. It is one of the success stories of the last twenty years. But more research is needed -- the therapies are not perfect, and they are not a cure. Numerous patients suffer from side effects and cannot tolerate the treatment. More needs to be explored in the administration of the therapies -- how much, how early, for how long, and in what combination. The research programs, especially the General Clinical Research Program, are vital to our learning more about this and related bone diseases. You and the NIH must make these studies possible, because we cannot do so on an effective enough level privately. And because we fall into the "orphan disease" category in terms of the size of our patient market, the pharmaceutical industry also is doing very little work to improve Paget's treatment.

The second main area of help we need is in education of the general public and of the medical profession. This fall the NIADDK published the first comprehensive brochure on Paget's disease, its symptoms, diagnosis, and treatment, that has been made available on a large scale. With the foundation's limited resources, it would have taken us years to produce it ourselves. We have already begun its distribution, and it has meant more to the sufferers of Paget's, who before had no information, than we can say. Even the physicians and nurses who write us are most enthusiastic about the usefulness of the brochure to themselves and to their patients. This production and circulation of printed materials by the Institutes of the NIH must continue -- how can a patient help himself to health without basic information? Our patients are beginning to receive the information now, but there is still a long way to go, as witnessed by the patient whose letter I just read to you.

In order to continue its programs which are so badly needed, the NIADDK must continue to be funded at an adequate level. The Paget's Disease Foundation would like to join in support of the Statement by the Coalition of Voluntary and Professional Organizations and ask for at least $475 million for the Fiscal Year 1983 for the NIADDK and for increased funding for all of the NIH.

Thank you.

STATEMENT OF ROBERT HUMPHREYS, WASHINGTON COUNSEL FOR THE ARTHRITIS FOUNDATION

Senator WEICKER. The next witness is Robert Humphreys, the Washington counsel of the Arthritis Foundation.

Mr. Humphreys.

Mr. HUMPHREYS. Good morning, Mr. Chairman.

Senator WEICKER. Good morning.

Mr. HUMPHREYS. Mr. Chairman, the problems of arthritis are pervasive: there are some 400 forms of rheumatic disease that we know of. Arthritis and related diseases are the number one crippler in the United States; 7 million people are disabled by it in its various forms, 37 million roughly have some form of arthritis.

The President's NIH budget, as you know, proposes a 1.8-percent increase in the budget for 1984, far below the 15 to 25 percent available for increases in other Federal research programs.

The proposed reallocation of funds undertaken to meet the need for 5,000 competing new and continuation grants would have a devastating effect on certain of the programs within NIH, and particularly those we feel relate to arthritis.

For example, half the existing multipurpose arthritis centers would be eliminated in fiscal 1984 and no new centers could be funded.

Beyond that, however, the Arthritis Foundation and its affiliated organizations—the American Rheumatism Association, the Arthritis Health Professions Association, and the American Juvenile Arthritis Foundation—are deeply disturbed by the projected allocation of funds within NIADDK.

And although we recognize that you don't impose directions to the Institute specifically in specific areas, we feel that because of the fact that we are the only division—the Arthritis, Musculoskeletal, and Skin Division—is the only one that is to be reduced absolutely in terms of 1983 continuing resolution, that we would like to urge you to renew the emphasis that Congress has recommended to NIH in the past with respect to arthritis research. Other divisions are expected—based on the President's budget—to increase from $2.8 to $8.6 million. Our division will be reduced by about $600,000 relative to 1983.

We have developed, or rather adopted detailed budget recommendations for the arthritis program in NIADDK. These coincide precisely with those of the National Arthritis Advisory Board, which will be addressing you next I believe; essentially we're recommending along with the board about $121 million for the Arthritis Division's research programs and we have the specifics of that attached to the written statement.

Arthritis and related diseases now take as much as $30 billion out of the economy; $1 billion a year is spent by arthritis victims on quack cures in their desperation and we urge that some minuscule portion of that expense be deferred and eliminated through attention to arthritis research programs.

PREPARED STATEMENT

And with your permission, Mr. Chairman, there is a coalition of organizations supporting NIADDK research which has developed a fact sheet and I would like to present those recommendations to the committee, the fact sheet, for inclusion in the record.

Senator WEICKER. It will be put in the record.

Mr. HUMPHREYS. Thank you, Mr. Chairman.

Senator WEICKER. Thank you very much.

[The information follows:]

Statement of the National Institute of Arthritis, Diabetes and Digestive and Kidney Diseases Coalition

The voluntary health agencies and professional societies listed below join in urging the Congress to approve a funding level of at least $475 million for the National Institute of Arthritis, Diabetes, and Digestive and Kidney Diseases (NIADDK) for Fiscal Year 1984. A fact sheet is attached discussing the Institute, its accomplishments, and its needs for the future.

We deeply appreciate the hard work and support of so many senators and representatives, and their staffs, over many years, in support of the National Institutes of Health (NIH) generally and NIADDK in particular. Historically, Congress has provided the initiative that has permitted NIH to grow and flourish. However, we are concerned that the total NIH research program stopped growing several years ago, and is significantly smaller than it was in FY 1979. Congress stopped the downward trend in the FY 83 budget, and we hope that it will act to allow NIADDK to take advantage of more opportunities in FY 84 than the President's budget would allow.

We recognize that biomedical research is interdependent, and we all support the overall effort of the NIH as well as the programs within NIADDK specifically. At a time when unprecedented opportunities are available, growth in research funding should allow full support of research efforts and adjustment for inflation. Anything less will have a direct, adverse impact on America's health far into the future.

Please call on us, individually or collectively, for any information or assistance you may need regarding funding f NIADDK. Thank you for your interest and support.

SUPPORTING ORGANIZATIONS

American Academy of Dermatology, Inc.
American Academy of Orthopaedic Surgeons
American Association for the Study of Liver Disease
American Brittle Bone Society
American Celiac Society
American College of Gastroenterology
American Diabetes Association
American Institute of Nutrition
American Gastroenterological Association
American Juvenile Arthritis Organization
American Liver Foundation
American Rheumatism Association
American Society for Artificial Internal Organs
American Society for Gastrointestinal Endoscopy
American Society of Hematology
American Society of Pediatric Nephrology
American Society for Parenteral and Enteral Nutrition
American Society of Transplant Surgeons
American Thyroid Association
American Urological Association, Inc.
Arthritis Foundation
Arthritis Health Professions Association
Center for Ulcer Research and Education Foundation
Children's Liver Foundation
Coalition of Digestive Disease Organizations
Cooley's Anemia Foundation for Children, Inc.
Cystic Fibrosis Foundation

Dean Thiel Foundation
The Dermatology Foundation
Dystrophic Epidermolysis Bullosa Research Assocn. (DEBRA)
Endocrine Society
Gluten Intolerance Group
Human Growth Foundation
Icthyosis Foundation of America
Juvenile Diabetes Foundation
Lupus Foundation of America
National Association of Patients on Hemodialysis
    and Transplantation
National Foundation for Ileitis and Colitis
National Hemophilia Foundation
National Kidney Foundation
National Neurofibromatosis Foundation, Inc.
National Psoriasis Foundation
North American Society for Pediatric Gastroenterology
Osteogenesis Imperfecta - National Capital Area, Inc.
The Paget's Disease Foundation, Inc.
Pediatric Liver Research Foundation
Renal Physicians Association
The Society for Investigative Dermatology
United Scleroderma Foundation

THE NATIONAL INSTITUTE OF ARTHRITIS, DIABETES, AND DIGESTIVE AND KIDNEY DISEASES (NIADDK) NEEDS $475 MILLION FOR FISCAL YEAR 1984

What is the mandate of NIADDK? To support research into a wide range of chronic, disabling, crippling, and debilitating diseases which account for a large portion of the total burden of illness in America.

The Institute's programs are divided into eleven areas: arthritis, musculoskeletal diseases, skin diseases, diabetes, endocrinology, metabolic diseases, digestive diseases, nutrition, kidney diseases, urology, and hematology. Included in the programs of these areas is research on cystic fibrosis, Paget's disease of bone, osteogenesis imperfecta (brittle bone disease), lupus, Cooley's anemia, hemophilia, scleroderma, liver disease, sickle cell anemia, psoriasis, dystrophic epidermolysis bullosa, dwarfism, and osteoporosis, as well as treatment for traumatic injuries and many other health concerns. It is safe to say that every American family can benefit from the successful fulfillment of the mission of NIADDK.

Has NIADDK succeeded in the past? During the 1970's due to the support provided by Congress, Institute-funded research produced major advances in nearly every area. Examples: development of artificial joints; control of gout; synthetic production of human insulin, somatostatin, and growth hormone, development of portable automatic insulin infusion pumps; new treatments for gastric and duodenal ulcer; advancement of endoscopic research; development of kidney transplantation and improved techniques of dialysis; successful induction of ovulation and pregnancy through hormone treatments; prenatal diagnostic tests for sickle cell anemia; and major improvements in the treatment of skin diseases.

What are the prospects for the 1980's? Scientifically, they are still excellent. Major breakthroughs in our basic understanding of immunology, genetics, recombinant DNA, and the roles of hormones, neurotransmitters, and other substances are being translated into practical improvements in all areas of the Institute's responsibility. The 1980's show great promise of allowing medicine to move from treatment of symptoms, to attacks at the underlying causes of chronic illness.

Is the President's budget adequate for NIADDK? No. The recommended increase of 1.8% for FY 84 would force a significant reduction in the pace of NIADDK research. Although the Institute did receive an increase in its 1983 budget, this followed a reduction in FY 82; the FY 84 budget adjusted for inflation is almost 10% below the level of three years ago.

Adjusted for inflation, the overall budget for NIH proposed by the President for FY 1984 is 14% less than that approved by Congress as recently as FY 1979. The 1.8% increase over FY 83 suggested by the President for NIH is only about one-third of the inflation rate, and far less than the 15% rise for all federal R&D activities contained in the budget.

NIADDK is especially hard hit because its budget has never recovered from the reduction during FY 82. During FY 81, the Institute funded 759 grants (41% of its applications); during FY 83 it expects to fund 720 grants (32% of its applications), but will reach this level only through cuts of 6-9% below approved amounts for grants and centers. If grants were fully paid, as was done in FY 81, the Institute would be able to make fewer than 500 awards. No detailed justifications have been submitted for FY 84, but it is clear that the amount requested will be inadequate even to maintain current activities.

Across-the-board reductions in grant payments may allow more grants to be funded, but reductions do not increase the amount of scientific research being performed. Instead, research projects are shortchanged, and the quality of science is reduced.

Because of inadequate funding, important research opportunities are being lost, and these trends, plus reduced training money, are convincing many good scientists that it is no longer advisable to plan on a career in biomedical research. Current funding patterns will directly translate into additional, but avoidable, deaths and disability during the latter part of this decade.

What is needed for NIADDK? We believe that the Institute should receive at least $475 million in FY 84, which will restore most, but not all, of the purchasing power NIADDK had in FY 81. At a level of $475 million, the Institute could fully fund those grants and programs it is now forced to support at a reduced level, and have a small budget to strengthen other important research programs as well, including research training, clinical trials, and centers. An appropriation of $475 million for NIADDK would still require almost two-thirds of scientifically-meritorious grant applications to go unfunded, but it would represent a major step toward promoting greater understanding of this important group of health problems.

An increase in funding for one institute is not adequate to meet the interdependent needs of biomedical research. We also support increased funding for all of NIH at a level that would offset inflation and provide real growth.

STATEMENT OF ROBERT HUMPHREYS

Mr. Chairman and members of the Committee, I am Robert Humphreys, Washington Counsel for the Arthritis Foundation, the only national voluntary health agency addressing research, professional training, patient education and services, and public education, with respect to the more than 100 forms of rheumatic disease. The Foundation has 71 chapters and divisions nationwide, supported by the work of professional staff and some 400,000 volunteers.

Arthritis is one of the nation's most pervasive chronic health problems, and is second only to cardiopulmonary diseases in its human and economic impact. Some 37 million of our citizens suffer from this family of diseases. Arthritis is America's number one crippler, and its victims are increasing by a million each year. Arthritis and related rheumatic diseases are not the exclusive province of the elderly; millions of working age adults suffer from these diseases, as well as some 250,000 children -- more than were claimed by polio during that dread disease's most virulent epidemic periods.

The President's FY 1984 budget for the National Institutes of Health proposes a 1.8 percent increase over the 1983 Continuing Resolution level, insufficient to meet even minimal inflationary costs, and far below the 15 to 25 percent increases for research and development awarded to other Federal programs. Aggravating this limitation is the Administration's decision to realine the allocation of funds within the requested amount to accommodate a level of 5,000 new research grants. The result of this proposed reallocation would be devastating to a number of NIH program areas, and would severely curtail individual investigator award amounts.

Within the National Institute of Arthritis, Diabetes, and Digestive and Kidney Diseases the arthritis research program, which in the past has suffered from totally inadequate funding in terms of the magnitude of the national health problem it addresses, would be cut still further. The arthritis, musculoskeletal and skin diseases division is the only division of NIADDK whose funding would be reduced under the reallocation. Half the existing multipurpose arthritis centers would be eliminated in FY 1984, and no new centers could be funded.

In FY 1982 NIADDK was the only NIH research institute to have its funds reduced. As a result, center grants, contracts, intramural research, and individual research project grants had to be cut. Only 31 percent of approved grants could be funded. The 1983 continuing resolution provided a substantial increase for NIADDK, but because of the need to recoup from the 1982 loss, in combination with other factors, even more substantial reductions in NIADDK research programs are scheduled for the current year. Such cuts permit a continued funding rate of 32 percent of approved grants, but the price is high.

The President's request for FY 1984, as revised in March, would have a dampening effect on NIADDK research overall, as I have indicated. This does not tell the entire story, however, and the Arthritis Foundation and its affiliated organizations, the American Rheumatism Association, the Arthritis Health Professions Association, and the American Juvenile Arthritis Organization, are deeply disturbed by the projected allocation of FY 1984 funds to the Division of Arthritis, Musculoskeletal and Skin Diseases.

Mr. Chairman, I indicated earlier that the arthritis research program in the past has been severely underfunded in relation to the magnitude of arthritis as a national health problem. This insufficiency is greatly exacerbated under the revised President's budget. The Arthritis Division is the only NIADDK Division slated for an actual decrease in funding below the FY 1983 level. In contrast, projected increases in the other Divisions range from $2.8 million to $8.6 million.

Although the Arthritis Division's investigator-initiated research project dollars would increase by $2.1 million over FY 1983, funding for Multi-purpose Arthritis Centers would be cut nearly in half, from $7.5 million to $3.8 million. Rather than giving increased emphasis to arthritis research, as Congress has long urged, Mr. Chairman, NIH and the Administration are constraining this vitally important area of research still further.

The level of funding that is needed and can reasonably and prudently be expended under the programs of the Arthritis, Musculoskeletal, and Skin Diseases Division of NIADDK substantially exceeds the President's budget amount and the intra-institute allocation for the next fiscal year.

The coalition of organizations supporting NIADDK research agree that, at a minimum, $475 million should be appropriated for the Institute for FY 1984. I ask that a copy of the fact sheet issued by the coalition be inserted at the appropriate point in the hearing record.

Beyond the coalition amounts, the Arthritis Foundation has adopted detailed budget recommendations for the Arthritis Division in FY 1984. These coincide precisely with the recommendations of the National Arthritis Advisory Board.

Exclusive of direct operations and program management costs, we urge the appropriation of an amount for NIADDK which would provide $120,993,000 for the Arthritis Division. Included in this amount are $78.53 million for research grants; $13.52 million for Multi-purpose Arthritis Centers, about $8 million for intramural research, and about $3 million for data and epidemiology. A detailed breakdown of the recommended amounts is attached as an appendix to this statement.

Mr. Chairman, the potential economic benefit to the nation, together with the widespread alleviation of pain and suffering that would result from the accelerated research effort implicit in our budget recommendations would be enormous. Arthritis and related diseases now take as much as $30 billion out of the nation's economy each year. A billion dollars a year are expended by arthritis sufferers on quack remedies. The number of people with rheumatic diseases is increasing by a million each year. With the aging of America the incidence of arthritis can be expected to increase as well. The National Center for Health Statistics ranks arthritis and musculoskeletal diseases second in overall adverse economic impact, and projects that expenses attributable to arthritis will reach nearly $100 billion by the year 2000.

Despite limited research funding on arthritis, which amounts to only about $1.50 per arthritis patient, many promising leads in the search to treat, cure, and possibly prevent arthritis have emerged over the past ten years. Total joint replacements have become almost commonplace surgical procedures. Drug therapy for gout has all but eliminated the pain of that disease. Genetic markers have been identified for many forms of arthritis, leading researchers to express strong hope for finding causes and, perhaps, cures.

Multi-purpose Arthritis Centers have been invaluable in developing innovative research, education, and community health care programs. More than 40 pilot research projects are underway at these centers, ranging from studies of infectious agents in joint inflammation, and genetics of major forms of arthritis, to studies of the immune system. Patient self-help programs, pain management, and public education in quackery and unproven remedies are examples of other center projects.

Epidemiology studies, so vital to improving our understanding of the bewildering array of arthritic disorders, are almost nonexistent. Better data and demographics will aid our knowledge of the etiologies of these diseases.

Accelerated funding of the arthritis research program would give much needed focus and vitality to arthritis research, and would attract capable young researchers to the field. There are few areas of medical research that have the potential for greater human and economic benefit than arthritis research. The arthritis program at NIH must be increased substantially, not reduced, if this nation is to succeed in curbing its most widespread, serious, chronic disease.

The Arthritis Foundation believes strongly that the Appropriations Committees and the Congress as a whole must adjust Federal funding priorities. The National Institutes of Health is a biomedical research institution that has no peer in the world. We are fearful, however, that America's pre-eminent position may be threatened by the erosion of attention given to it.

We urge this Committee to incorporate the budget recommendations of the Arthritis Foundation and the National Arthritis Advisory Board in the FY 1984 appropriations for the National Institutes of Health. These amounts have been determined after careful study and analysis by prominent researchers and lay experts in the field of arthritis.

We ask you to consider that expenditures for quack cures are 25 times as high as the investment in research, and that research gains hold the promise of dramatically reducing the drain on the Nation's economy and of relieving the suffering of millions of its citizens. We are hopeful that, when you have considered the cost of arthritis, you will agree with us that realistic funding for research is an excellent investment, and the dividends of that research will be profoundly important to the people of our land.

That concludes my testimony, Mr. Chairman. I will be pleased to respond to any questions the Committee may have.

ARTHRITIS FOUNDATION
BUDGET RECOMMENDATIONS FOR FISCAL YEAR 1984
ARTHRITIS DIVISION NIADDK

(Thousands of Dollars)

Research grants	$ 78,530
Modernization of equipment and facilities for extramural arthritis research	4,000
Multipurpose Arthritis Centers	13,520
Other research: Research Career Development Awards, Clinical Investigator Awards, data systems research, scientific workshops	4,500
National Research Service Awards (training)	4,725
Research and development contracts	3,635
Epidemiology	2,000*
Data	950*
Education and training, conferences, seminars, and workshops	900
NIH intramural research	7,973
Arthritis Information Clearinghouse	200**
TOTAL	$ 120,933***

These budget recommendations would fund research grants to a priority score of 220. It would fund 47% of all approved grants and 52% of approved funds. Currently grants are funded to a priority score of 180 with an award rate of 32%.

* Not included in recommendations for research grants.
** In addition to $200,000 currently included in research and development contracts recommendations.
***Program dollars only, does not include administrative costs.

STATEMENT OF RONALD LAMONT-HAVERS, M.D., VICE CHAIRMAN, NATIONAL ARTHRITIS ADVISORY BOARD

Senator WEICKER. Dr. Ronald Lamont-Havers, vice chairman of the National Arthritis Advisory Board.

Dr. LAMONT-HAVERS. Thank you, Mr. Chairman.

Mr. Chairman, as you know, the National Arthritis Advisory Board was established by Public Law 95-562 in October 1976 and the authorization was renewed by Congress in 1980 and, among other things, we do submit an annual report to Congress on the activities of our overview of the national arthritis plan, which was presented by the National Commission on Arthritis.

The current annual report, Mr. Chairman, will be submitted to Congress within the next few days, and my written testimony will summarize the recommendations of the board specifically as they relate to the fiscal year 1984 budget of NIH and the Arthritis Division of NIADDK. I won't go into that in any great detail right now, Mr. Chairman.

All of the budgetary categories of the board's report will document and justify the need for these levels of expenditures. Although the other concerns of the board such as research, training, education, and epidemiology are full of immediate promise for the victims of arthritis and rheumatic diseases, I would like to concentrate at this time on the need to support to the multipurpose arthritis centers, the so-called MAC's.

The National Arthritis Act of 1974 called for the establishment of a series of comprehensive arthritis centers and in response to this mandate a centers program was initiated by the NIADDK in 1977. Currently 20 centers receive grants from the Institute to develop innovative programs in arthritis research and to initiate education and community programs.

This board is concerned with the future of this most productive program. Ten of the strongest and most influential centers will be up for competing renewal in fiscal year 1984, and I'm aware, Mr. Chairman, that you know the identity of these centers so I won't list them.

In addition to those which will be phased out through the Division's efforts which were stimulated by the board, applications for new centers have also been received from such medical schools as the University of Pennsylvania and the Mayo Clinic. In addition. the single Arthritis Core Center to support an excellent research complex at the Brigham and Women's Hospital, Harvard Medical School, is also up for competing renewal in fiscal year 1984 and, therefore, under the administration's budget, will be phased out.

The administration's budget would prohibit the continuation of these programs. Not to be able to consider funding of these major multipurpose arthritis centers and core centers which have contributed so much to the advancement of scientific knowledge, education and care in arthritis and the other rheumatic diseases would be a great tragedy and one understood only with great resentment by the millions of arthritis sufferers.

It does seem ironic that the board had considered that the time was now right with regard to the advances in scientific knowledge that we should recommend specialized centers of research. The proposed budget strategy will have adverse effects for years to come and will be a bitter blow to such opportunities.

The board has also shown deep concern for the continuing support of the regular research program. We support with the rest of the scientific community the need to stabilize the research program. It is shocked, however, by the methods proposed in the fiscal year 1984 budget to meet these desired goals. The continued cut in the regular research program even at the level suggested will have a major destabilizing effect upon the biomedical community. Certainly also the 10-percent reduction in indirect costs is simplistic, naive, and jejeune.

Thus, the National Arthritis Advisory Board's recommendation for 1984 is in excess of that proposed by the administration. These recommendations, however, more nearly reflect the true need to continue an effective research program so vital to our society.

Thank you, Mr. Chairman.

Senator WEICKER. Now the difference mainly comes, as I gather it, in the centers that you feel could not be funded under the proposed budget; is that correct?

Dr. LAMONT-HAVERS. Yes, Mr. Chairman, we are particularly concerned with the centers that would be phased out.

Senator WEICKER. OK. Which ones did they indicate were the ones——

Dr. LAMONT-HAVERS. All of these were the ones.

Would you like me to——

Senator WEICKER. No; I've got them.

Are we all of a mind here—Michigan University; Brigham and Women's Hospital, Boston; Arizona Medical; Washington University, St. Louis; Stanford; Boston University; Alabama University; the University of California, San Francisco; University of Connecticut; State University of New York; University of Missouri and the Arthritis Core Center, Brigham and Women's Hospital, is that right?

Dr. LAMONT-HAVERS. That's right, Mr. Chairman.

I think it's ironic that the center in San Francisco is called the Rosalind Russell Center at the request of Congress and that's one of the ones that will be phased out.

PREPARED STATEMENT

Senator WEICKER. Thank you very much. I appreciate your honesty.

[The statement follows:]

STATEMENT OF RONALD LAMONT-HAVERS, M.D.

Mr. Chairman and members of the subcommittee, I am Dr. R. W. Lamont-Havers testifying today as vice-chairman of the National Arthritis Advisory Board in support ot the FY'84 budget of the Division of Arthritis, Musculoskeletal and Skin Diseases of the National Institute of Arthritis, Diabetes, Digestive and Kidney Diseases, particularly as it affects the need to continue the fight to overcome arthritis.

The National Arthritis Advisory Board was established by PL 94-562 in October of 1976 and the authorization was renewed by Congress in 1980. It had been formed as the result of recommendations in the Arthritis Plan developed by the National Commission on Arthritis and Related Musculo-skeletal Diseases in April 1976. This Plan contained an analysis of major areas such as research, education and training, data systems and epidemiology, arthritis centers, and community programs. Ongoing functions of the Board are to review and evaluate the effectiveness of the Arthritis Plan, amend it where appropriate and to submit annual reports to Congress on its activities.

Mr. Chairman, the current Annual Report will be submitted to Congress within the next few days. At this time, however, I would like to summarize the recommendations of the Board specifically as they relate to the FY'84 budget of the NIH and the Arthritis Division of the NIADDK.

Arthritis, in its more than 100 forms, is both a crippler and a killer. It is well-known that 35 million Americans--about 1 in 7, or 15% of the population--suffer from arthritis and related musculoskeletal diseases. Included are not only rheumatoid and osteoarthritis, the two more common forms, but also other important conditions of systemic lupus erythematosus, scleroderma, ankylosing spondylitis, juvenile arthritis, and many other equally debilitating diseases.

Previous estimates compiled by the National Center for Health Statistics and other sources of the costs resulting from various diseases rank arthritis and related musculoskeletal diseases as second in overall adverse impact among all American citizens. These estimates also project that in the year 2000, expenses attributed to arthritis will consume 4.6% of the total health outlay, or approximately $96.8 billion. As the Nation's number one crippler, arthritis is also responsible for an increasing number of persons leaving the work force before attaining normal retirement age. The resultant loss of earnings is staggering; current estimates place this figure at $25 billion a year.

Contrary to popular belief, arthritis is not just a disease of old age. Although it affects more than 40 percent of people over age 65, arthritis can strike people in any age group. Estimates are that 250,000 children under 18 have arthritis or a related joint disease, and 100,000 of these children will carry crippling handicaps into their adult years. Some forms of juvenile arthritis can cause crippling of limbs, kidney disease, blindness, and even premature death. Arthritis affects women twice as often as men, and it is most prevalent among low-income and rural populations. Since the Nation's elderly citizens are expected to increase from 10 percent to 20 percent of the total population by the year 2030, the prevalence of arthritis can be expected to increase as well.

The recommendations for the FY'84 budget of the Division of Arthritis, Musculoskeletal and Skin Disease of NIADDK is outlined below. In presenting its recommendations for the FY'84 budget, the Board recognizes the need for fiscal constraint in the Nation's current economic climate. However, in view of the extent, long-term nature, and enormous costs of rheumatic disease to our society--both in terms of human suffering and in terms of economic and social impact--the Board believes that these expenditures are necessary and justified. They will, in the long run, result in a better understanding of the causes of arthritis, improved treatment techniques, better care for patients, and, it is hoped, in the ultimate eradication of rheumatic diseases and their tragic consequences.

BUDGET RECOMMENDATIONS FOR FISCAL YEAR 1984
NIADDK DIVISION OF ARTHRITIS, MUSCULOSKELETAL AND SKIN DISEASES
(Thousands of Dollars)

Research Grants	$78,530	National Research Service Awards (training)	4,725
Multipurpose Arthritis Centers	13,520		
Specialized Centers of Research	$2,000	Education and Training, Conferences, Seminars, and Workshops	900
Research & Development Contracts	$3,635	Epidemiology	2,000*
Modernization of Equipment and Facilities for Extramural Arthritis Research	4,000	Data	950*
NIH Intramural Research	7,973	Arthritis Information Clearinghouse	200+
Other Research: Research Career Development Awards, Clinical Investigator Awards, Data Systems Research, Scientific Workshops			4,500

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*Not included in recommendation for research grants

+In addition to $200,000 currently included in research and development contracts recommendations

In all of these categories the NAAB Report will document and justify the need for these levels of expenditures. I am sure that many of the public witnesses speaking on behalf of the NIADDK budget will highlight the great advances being made in arthritis research and the bright probabilities of new discoveries in the near future. These were highlighted in a recent workship sponsored by the Division of Arthritis and Musculoskeletal and Skin Diseases and will be dealt with in greater depth in this Board's final report scheduled for later this year.

Although this area is indeed exciting and the other concerns of the Board such as training, education and epidemiology full of immediate promise for the victims of arthritis and the rheumatic diseases, I would like to concentrate at this time on the need of support for the Multi-purpose Arthritis Centers (MACs). The National Arthritis Act of 1974 (PL 93-640) called for the establishment of a series of comprehensive arthritis centers. In response to this mandate, a Centers Program was initiated by the National Institute of Arthritis, Diabetes, Digestive and Kidney Diseases in FY 1977.

Currently, 20 centers receive grants from NIADDK to develop innovative programs in arthritis research and to initiate education and community programs. MACs are designed to demonstrate and stimulate prompt and effective application of available knowledge for the treatment of pateients with arthritis and related musculoskeletal diseases as well as to develop new knowledge for the control of these disorders. Each center engages in basic research on the causes of the disease, carries out pilot and feasibility studies for developing investigators, supports education and training activities, and encourages the community application of evolving methods of treatment.

In order to obtain NIADDK support, a MAC must have an active, excellent program in basic and/or clinical research. Center funds may not be used to support ongoing research projects, but may be applied to developmental and feasibility studies, as well as to core units that provide centralized research resources.

The NAAB placed special emphasis during the past year on an analysis of the MACs and their programs. As part of this study the whole Board undertook site visits to the two MACs situated in Boston--one at Boston University's School of Medicine and the other at Brigham and Women's Hospital-Harvard Medical School. These two Centers epitomized the ability of individual MACs following the same general guidelines to develop excellence and diversity in research, education and community interaction programs. The NAAB was impressed with the accomplishments of the MACs and these findings will be documented more fully in the final report of this Board due later this year.

This Board is concerned with the future of this most productive program. Many of the strongest and most influential Centers will be up for competeing renewal in FY'84. These include those at the University of Alabama,University of Michigan Medical School, University of Arizona, Boston University School of Medicine, University of California at San Fransisco - The Rosalind Russell Arthritis Center, Washington University in St. Louis, Downstate Medical Center in New York, Brigham and Women's Hospital-Harvard Medical School, University of Connecticut School of Medicine, the University of Missouri Medical Center and Stanford University Medical School. In addition, through the Division's efforts, which were stimulated by the Board, applications for new centers have also been received from such medical schools as the University of Pennsylvania and the Mayo Clinic.

In addition, the single Arthritis Core Center to support an excellent research complex at the Brigham and Women's Hospital - Harvard Medical School is also up for competing renewal in FY'84.

The Administration's FY'84 budget would prohibit the continuation of these programs. Not to be able to consider funding of these major Multipurpose Arthritis Centers and Core Center, which have contributed so much to the advancement of scientific knowledge, education and care in arthritis and the other rheumatic diseases would be a great tragedy and one understood only with great resentment by the millions of arthritis sufferers.

It does seem ironic that the Board had considered that the time was now ripe with regard to the advances in scientific knowledge that a new phase in Center development should be initiated. These would be Specialized Centers of Research which could bring to bear an intensive multidisciplinary effort in such areas as Rheumatoid Arthritis and Osteoarthritis. The Administration's proposed FY'84 Budget strategy which will have adverse effects for years to come will be a bitter blow to such opportunities.

The Board has also shown deep concern for the continuing support of the regular research grant programs. In concert with the scientific community generally, the Board is convinced that these programs are vital to the strength and productiveness of the American biomedical research effort. It has thus supported the concept of stabilizing the number of regular research grants, and this concept has been adopted by the Administration. It is shocked, however, by the methods proposed in the FY'84 budget to meet this desired goal. During the present fiscal year the NIADDK was forced to cut continuing research grant awards by 8% and new grant awards by 15% in order to meet funding obligations.

For FY'84 it is proposed that the direct costs of new and competing continuation grants be cut by 11.1% and those of non-competing continuation projects by 4.6%, that there be no new or competing continuation centers, and a 10% reduction in indirect costs--the latter being a particularly simplistic, naive and jejune solution to an extremely complex and pressing problem.

The constraints upon the Administration's officials and administrators are recognized. It does not seem reasonable, however, to justify the drastic steps being proposed to limit the federal support of biomedical research under the guise of seeking stability. In fact, this proposed budget will have a serious destabilizing effect upon the biomedical community.

Since 1980, funding for arthritis research has been far below amounts recommended by NAAB and the levels cited in the Arthritis Plan. Inflation, coupled with budget cuts, threatens promising research programs and imposes severe strains on the biomedical research community. When only about one-third of approved grant applications can be funded, as has been the case in the arthritis program in recent years, promising research is jeopardized and research teams, developed over the years, are disrupted. Renewal of support in later years is rarely sufficient to regain this lost momentum.

Thus, the National Arthritis Advisory Board's recommendation for the FY'84 Budget of the Division of Arthritis, Musculoskeletal and Skin Dieseases (NIADDK) is in excess of that proposed by the Administration. These recommendations, however, more nearly reflect the true need to continue an effective research program so vital to our society.

STATEMENT OF JAMES B. FIELD, M.D., CHAIRMAN, NATIONAL DIABETES ADVISORY BOARD

Senator WEICKER. Next we have Dr. James Field, chairman of the National Diabetes Advisory Board.

Dr. Field.

Dr. FIELD. Mr. Chairman, I'm Dr. James Field, chairman, National Diabetes Advisory Board and professor of medicine at Baylor College of Medicine in Houston.

As you know, the National Diabetes Advisory Board was established by Congress to review and report to Congress and the Secretary of Health and Human Services concerning the Federal program in diabetes.

The annual report of the National Diabetes Advisory Board will be sent to you and the rest of Congress in a week or so, but I would like to report that if one compares the report that you'll receive very soon with the one in 1975, one can see the tremendous progress which has been made in relation to diabetes, and I think it certainly justifies the investment and the wisdom of Congress in increasing in the mid-1970's the appropriation for diabetes research.

Nonetheless, the problem of diabetes is still a very large one. Between 5 and 10 million Americans suffer from diabetes, with an economic impact of the disease on this country of approximately $10 billion. One-fourth of all the patients entering chronic renal dialysis programs are now patients who have diabetes and because of the diabetes they have renal failure.

Diabetes is probably the single most common cause of new blindness in the adult. Diabetes is responsible for more amputations related to nontrauma than any other disease. In fact, it's been estimated that the cost to the Federal Government of renal dialysis alone for diabetic patients is $400 million a year, almost three times the total amount of money which the Federal Government appropriates for diabetes-related research.

If one compares the annual report which you'll soon be receiving with the one which was the first one of the Board in 1975, one can see the tremendous advances that have been made related to our understanding of diabetes and the potential cure and elimination of the complications which represent the economic burden of the disease.

For example, we now have much greater information concerning immunologic and genetic contributions to the etiology of diabetes. It now may be possible to identify people who are destined to become diabetics and perhaps institute preventive measures which might prevent the disease.

We're now able in experimental animals to transplant the tissue that makes insulin across species barriers and hopefully because of advances in eyelet cell transplantation which may be applicable to other organ transplantation, one may be able to talk about total amelioration of the disease.

Recombinant DNA technology which is tremendously exciting has now made it possible to produce unlimited supplies of insulin for the diabetics of the world. At one point there was concern that there would not be sufficient animal pancreases to provide sufficient insulin for the diabetics by the end of the 1990's; this is no longer a problem.

The relationship between the control of diabetes and the complications is a very important current question in diabetes and is the subject of a cooperative trial supported by the National Institute of Arthritis, Diabetes, Digestive, and Kidney Diseases. But this trial will not go on if the President's recommended budget is adopted.

There are a series of other advances which are outlined in the formal testimony which we've submitted but which time does not permit me to delineate.

I would like to emphasize, however, that since 1979 in constant dollars the budget of the National Institutes of Health has actually decreased and the budget of the National Institute of Arthritis, Diabetes, Digestive, and Kidney Diseases, which is the lead institute for diabetes, has also decreased in constant dollars since 1979.

Our recommendations which are in our testimony would ask for $505 million for the Institute of Arthritis, Diabetes, Digestive, and Kidney Diseases and $102 million for diabetes research itself.

The justification for this is clearly outlined. This really represents a restoration of the cuts which have been introduced this year, permits the clinical trial which answers the most pressing question in diabetes as to whether control of the blood sugar would prevent the complications and will continue to support diabetes centers.

We also have recommended that there be a $9 million appropriation for the Centers for Disease Control, because this program has translated the research advancements into improved diabetic care in a large number of States in the country.

I appreciate very much the opportunity to present this information to you and would be happy to answer any questions.

Senator WEICKER. Is the clinical trial that you refer to one of those that was scheduled for a cut or for elimination?

Dr. FIELD. Yes; all clinical trials would be eliminated under that budget. And this is one which has just been initiated, the first patients were entered into it in February. It's a long-term trial because one needs the long term to draw appropriate conclusions from the study.

PREPARED STATEMENT

Senator WEICKER. Thank you very much, Doctor.

[The statement follows:]

STATEMENT OF JAMES B. FIELD, M.D.

I am Dr. James B. Field, Professor of Medicine at Baylor College of Medicine, Houston, Texas. I represent the National Diabetes Advisory Board, which was established by Congress to review and evaluate the implementation of a long-range diabetes plan and to report annually to Congress and the Secretary of HHS on recommendations for future policies, programs, and budgetary requirements. The Board recently completed its annual report which will be printed and sent to you shortly. The report describes the tremendous progress of the diabetes program during the last few years and the significant opportunities for future advances both in research and its application to treatment. These accomplishments have already begun to have a significant impact on the tremendous economic burden of the disease and the quality of life of individuals with diabetes.

A comparison of the Board's report and the 1975 report of the National Commission on Diabetes demonstrates the remarkable progress which has been achieved through increased support for diabetes-related basic research by the National Institutes of Health. The following research accomplishments reflect considerable progress toward the ultimate prevention or cure of some forms of the disease and reduction of some of its complications.

o A major role for immunological and genetic factors in the development of insulin-dependent diabetes has been demonstrated. This information may facilitate identification of persons at greatest risk for this type of diabetes and permit initiation of preventive therapy prior to or during the development of clinical symptoms.

o Basic research advances in immunology and tissue culture have demonstrated the feasibility of transplanting islet cells across major strain and species barriers. Segmental pancreatic transplantation has been successfully accomplished in conjunction with kidney transplants in a significant number of diabetic patients.

o The insulin gene has been isolated and its complete structure elucidated. Production of human insulin by recombinant DNA technology now assures adequate supplies of this essential hormone. A more fundamental understanding of the process of insulin synthesis, storage, secretion, and action has been achieved.

- Considerable animal data and preliminary results in humans indicates that more meticulous control of blood glucose and blood pressure can delay or reverse some of the changes characteristic of diabetic retinopathy, kidney disease and neuropathy.

- The development of insulin pumps now permits the near normalization of blood glucose for prolonged periods of time. While these devices are not ready for general use, they will facilitate studies to determine whether the complications of diabetes and their associated economic burden can be reduced, delayed, or prevented by rigorous contol of blood glucose. (Such a study, the Diabetes Control and Complications Trial, has been initiated by the NIADDK. However, funds to continue this important study beyond the current feasibility phase are not available.)

- Aggressive insulin treatment of the mother and monitoring of the fetus can reduce most of the complications of diabetic pregnancy to a rate comparable to those in non-diabetic pregnancies.

- Clinical studies have established that photocoagulation significantly reduces the risk of blindness from proliferative diabetic retinopathy.

- The success rates for both dialysis and kidney transplants in diabetic patients have improved to the point where the outcome is almost as good as for the non-diabetic patient.

These few examples emphasize the Board's belief that diabetes presents one of the best opportunities in medicine to apply research advances for the prevention and treatment of a disease. While investigators continue to seek basic and fundamental information which will eventually lead to the prevention and cure of the disease itself, the cost-effective application of current diabetes treatment information is being demonstrated through improved diabetes control programs which effectively integrate medical knowledge and public health disease control practices. For example:

- In Maine, initial results from a patient education program conducted in 37 hospitals and rural health centers throughout the state demonstrated a 31% reduction in diabetes-related hospital days with a resultant savings of almost three times the cost of the educational program. Diabetes control projects in other states, sponsored by the Centers for Disease Control, are demonstrating similar cost-effective results of intervention programs.

Based on these accomplishments, the future offers considerable hope. Diabetes research is poised at the edge of a "golden age." However the magnitude of the diabetes problem and the numerous opportunities to achieve significant reductions in the scope and impact of this disease are not reflected in recent budget appropriations for Federal diabetes-related programs. The appropriations have not kept pace with inflationary cost increases. A major tragedy of immense proportion will result if the current opportunities and the previous Federal investment in the diabetes program are not fully exploited to reduce the morbidity, mortality, and associated economic and social burden of this disease. Current budgetary proposals are an ironic example of short-sighted policy, since a major portion of the economic burden of diabetes directly affects the Federal budget through Medicare and Medicaid, other programs of the Public Health Service, and health care activities of the Veterans Administration, the Indian Health Service, and the Department of Defense. For example:

- Kidney Dialysis: The average annual cost of kidney dialysis is about $25,000 per patient. Since persons with diabetes comprise 20-25 percent of all new cases of end-stage renal failure, the direct annual diabetes-related cost of these medical procedures totals approximately $400 million, over twice the total amount of money spent by the Federal government for all its diabetes-related research. These costs are born primarily by the Medicare funded End-Stage Renal Disease Program.

- Amputations: About 20,000 amputations occur annually in persons with diabetes, representing approximately 50 percent of all non-traumatic amputations in the country. The hospital costs alone of these amputations are about $250 million, more than the total Federal expenditures for diabetes research. A significant portion of this total is borne by the Medicare/Medicaid program, the Veterans Administration, and the Indian Health Service.

- Blindness: Diabetes is one of the leading causes of blindness in the adult with about 5,000 new cases occurring each year. Federal-State disability payments, benefits and rehabilitation services for these person total about $45 million annually.

More effective dissemination and widespread application of current treatment information can reduce some of the morbidity, mortality, and resulting economic burden which diabetes places upon the society in general and upon Federal health care programs in particular. However, current opportuntities in biomedical research offer the even brighter potential of preventing or curing some forms of the disease itself, thus eliminating complications in many individuals. In view of these opportunities, we would anticipate that diabetes research and cost-effective programs to transfer current and future treatment advances to the patient would receive a very high priority. Most of the recent advances in our understanding of diabetes and treatment of the complications directly reflect the increased Federal support of the diabetes program in the mid 1970's. However, in the past several years, this impetus and support have not been maintained. The agencies with the greatest opportunities now are struggling to simply maintain current programs. The gap between the budgets recommended by the Board, based on these opportunities, and the actual Federal appropriations has inexorably continued to widen.

- The Research Program: Approximately 90 percent of the Federal research effort in diabetes is supported by the National Institutes of Health. When adjusted for inflation and expressed in terms of constant 1975 dollars (the start of the diabetes initiative), the total NIH support for diabetes research reached a peak in FY 1979 and has subsequently declined each year through FY 1982. The diabetes budget for the National Institute of Arthritis, Diabetes, Digestive and Kidney Diseases (NIADDK), the lead agency for diabetes research, followed a similar pattern and is now at a lower level (in constant dollars) than comparable funding levels for FY 1978. The NIADDK diabetes program has historically funded approximately 45 percent of approved, scientifically meritorious, research applications. This percentage has now declined to approximately 30 percent and would be at 20 percent if a decision had not been made to administratively reduce the previously awarded budgets of noncompeting grants in order to fund some additional competing awards in the current year. Support for training of research manpower has not been sufficient to provide the number of new investigators necessary to maintain the current pool of scientists doing diabetes related research.

- National Diabetes Control Program: This imaginative program, conducted in twenty states and supported by the Centers for Disease Control, has been severely hampered since its inception because of inadequate funds to fully support intervention projects which are demonstrating their cost-effectiveness.

Recommendations

The Board believes that the advances and opportunities summarized in this report justify a strengthened and expanded diabetes program to 1) seek more basic and fundamental information leading to the prevention or cure of the disease itself, and 2) develop and evaluate improved methods immediately applicable to the treatment of diabetes and the prevention or reduction of the severity of its disabling complications. A long range budget for these activities was developed and recommended three years ago by the Board. Unfortunately, severe budgetary restrictions in recent years have resulted in an increasingly large discrepancy between the current budget and those recommendations. Although the previous recommendations still realistically represent the program's needs, the Board has provided new recommendations for FY 1984 which represent the minimum resources necessary to continue the program at the current level of effort and provide full support to essential activities which have not kept pace with cost increases of recent years.

National Institutes of Health: The Board recommends that Congress provide $505 million in FY 1984 for the National Institute of Arthritis, Diabetes, Digestive and Kidney Diseases (NIADDK), including $102 million for diabetes-related activities within NIADDK. This budget will restore full, recommended support for noncompeting investigator-initiated research grants in diabetes and related areas. It will permit funding of new and competing research grants to the paylines and award rates realized during fiscal years 1977-1980. In addition, these resources will fully support the NIADDK's 11 diabetes centers, research training and related manpower development awards, and the Diabetes Control and Complications Trial. The Board also recommends the following budgets in FY 1984 for diabetes-related activities of other NIH Institutes to fully capitalize on new and promising opportunities in their respective areas of responsibility: NHLBI, $19.5 million; NEI, $24 million; NICHD, $11.2 million; NINCDS, $7.3 million; NIAID, $5.8 million; NIA, $3 million; NIDR, $2.6 million; NIGMS, $1.5 million; NIEHS, $.2 million; and DRR $17.7 million.

Centers for Disease Control: The Board recommends that Congress provide $9 million in fiscal year 1984 to continue and expand the National Diabetes Control Program at the Centers for Disease Control. This budget includes funds to continue the current effort, to expand the program to five additional states, to provide start-up costs for new or upgraded community patient education services and to implement one or two community-wide demonstration efforts.

STATEMENT OF CHRISTOPHER SAUDEK, M.D., CHAIRMAN, GOVERNMENT RELATIONS COMMITTEE, AMERICAN DIABETES ASSOCIATION

Senator WEICKER. Dr. Christopher Saudek, chairman of the Government relations committee of the American Diabetes Association.

Dr. SAUDEK. Mr. Chairman, I am Christopher Saudek of the Johns Hopkins University School of Medicine, associate professor of medicine and chairman of the Government relations committee of the Diabetes Association.

I am here to testify on behalf of the American Diabetes Association, with its 180,000 members, 700 chapters in the United States and represented in all 50 States; but more I'm here to testify on behalf of the approximately 6 million American diabetics.

We call for an appropriation to the National Institutes of Health of $481 million for a 12-percent increase over fiscal year 1983 and a 15-percent increase to $475 million for the National Institute of Arthritis, Diabetes, Digestive, and Kidney Diseases.

We also call for increases in the Veterans' Administration research, the communicable disease centers, and Indian Health Service.

Patients now check their own blood sugar accurately and virtually painlessly; the eye complications are being substantially improved by the treatment with laser beam therapy, and we have a variety of insulin pumps which patients can wear on their belt.

Speaking personally, I am involved in the implantation of insulin pumps and a highly computerized and programmable implantable insulin infusion pump under the skin of dogs now and hopefully patients in the near future.

These advances have been made possible by the direct result of the support of this committee through research funded by the NIH. And we are in a phase now of huge productivity in NIH research and my fundamental message is that the increases called for in the President's budget, as you said yourself, are woefully inadequate to maintain the level of biomedical research

Our level of funding is listed and defended in the legislative position that's been submitted to the committee. The level of $475 million for the Arthritis, Diabetes, Digestive, and Kidney Disease Institute is a minimum, stand-pat budget to allow for continuation of the programs that are currently underway at the same level of effort as in the past. We, therefore, consider this to be a minimum budget and one that would just maintain the level of activity currently.

Thank you, Mr. Chairman.

PREPARED STATEMENT

Senator WEICKER. Thank you very much, Dr. Saudek.

[The statement follows:]

STATEMENT OF CHRISTOPHER SAUDEK, M.D.

Introduction

Mr. Chairman, the American Diabetes Association appreciates the opportunity to appear again before this Subcommittee. I am Christopher Saudek, M.D., Chairman of the Government Relations Committee of the American Diabetes Association, Associate Professor at Johns Hopkins University School of Medicine, and a member of the Board of Directors and member of the Public Affairs Committee of the Maryland Affiliate of the American Diabetes Association.

1. THE PROBLEM

According to the National Diabetes Advisory Board, a high level board established in 1976 by Congress, diabetes affects almost 6 million people in the United States. Approximately 30% of these require insulin on a daily basis, many beginning in childhood. Furthermore, several million additional persons may have undiagnosed noninsulin-dependent diabetes.

- Each year, approximately 5,000 diabetic patients become blind. Thus, diabetes is a major cause of blindness.
- Diabetes is responsible for almost 50 percent of the amputations of the foot and leg among adults.
- Diabetes is responsible for about 20 percent of all cases of kidney failure.
- Infants born to mothers with diabetes have an increased rate of mortality, congenital malformations, respiratory distress, and other serious medical problems.
- Diabetes is one of the four major risk factors for cardiovascular disease.
- Diabetic patients spent twice as many days in the hospital as persons without this disease. Over 2 million individuals with diabetes require hospitalization each year.

The cost of diabetes increases daily. Since the National Commission on Diabetes submitted its report in 1975, the cost of medical care for the diabetic patient and the losses due to disability and premature mortality have almost doubled to $9.7 billion annually. Each year, patients with diabetes account for over 19 million visits to physicians and for 10 percent of all hospital days, for a total of more than 21 million hospital days. One in every seven patients in nursing homes has diabetes.

2. GENERAL POSITION ON DISCRETIONARY HEALTH PROGRAMS

At a time when Medicare and Medicaid programs and Department of Defense spending are consuming an ever-larger share of the Federal budget, there is increasing pressure to reduce expenses in other areas, such as the $7 billion "discretionary" health budget. But this "discretionary" budget includes biomedical research and other programs with a direct impact on the health care of America's people.

The American Diabetes Association, therefore, supports continuing expenditures in these "discretionary" health programs at a FY 1984 level that at least maintains FY 1983 levels of services and activities. Such public policy reconfirms the philosophy that yearly fiscal pressures should not unfairly affect health service and research programs that were many years in the making and would take many years to repair.

3. THE IMPORTANCE OF BIOMEDICAL RESEARCH: THE NIH BUDGET

This Subcommittee has been a protector and advocate of the NIH and its programs for many, many years. The preeminent position of the United States in biomedical research and technology, an important element in our overall strength as a nation, is due in no small part to this Subcommittee. Yet, Mr. Chairman, we of the American Diabetes Association believe that our ability to maintain this preeminent position is in jeopardy. Certainly the Administration budget for NIH research in FY 1984 makes biomedical science a second class citizen relative to most other Federally-sponsored research. While other Federal research and development budgets increase by 17% in the Administration's FY 1984 proposal, the NIH budget increases by only 1.8%. An increase of only 1.8% would severely set back biomedical research. However total Administration budget numbers are internally shuffled, an increase of only 1.8% is far short of that necessary to maintain the current research effort of NIH. We believe that an addition of about $487 million over FY 1984 is needed to achieve the object of continuing the current FY 1983 level of effort. That increase (14%) would still be less than the rate of increase for other Federal R&D budgets.

Examples of Research Advances & Opportunities

Mr. Chairman, let me spend a few moments describing the state of research in diabetes to give the Subcommittee a sense of the great accomplishments we are making. During the past 8 years, since the National Diabetes Act, support for diabetes research activity by NIH has increased substantially and the number of important research advances has increased even more. Often, these discoveries have generated further important research opportunities. And, in many cases, they have been the basis of improved treatment.

Research regarding DNA has led us to discover methods of creating human insulin. This has several medical advantages, including the assurance of a continuing supply of insulin. It is one of the first examples of recombinant DNA technology moving into commercial production.

Second, treatment methods using laser beams have been developed which reduce blindness for those with diabetic retinopathy. A large clinical trial funded by the NIH proved the benefits of laser treatment, and now it is being tested for efficacy in earlier stages of diabetic eye disease. This advance alone is saving and will save both human suffering and disability support. Laser treatment on those with advanced retinopathy has been proven to reduce the risk of severe visual loss by 60%. The application of these advanced treatment methods for diabetic retinopathy has been recommended by NIH to Secretary Schweiker as a major national "Prevention" initiative.

Third, automated systems for delivering insulin have been developed so that insulin delivery to the diabetic can be precisely and accurately regulated. This technology is in large part a result of space program microelectronics, and is already benefitting thousands of diabetics.

Fourth, there are, in the words of NIH, "breakthrough" studies on transplantation of insulin-producing cells in animals. Not only does this promise to be a great advance for diabetics, but for immunology and organ transplantation generally. If perfected, transplants might provide a "cure" for diabetes.

Finally, a major clinical trial is underway in diabetes. This trial will test the impact of strict control of blood sugar on the development of eye disease, heart disease, kidney and nerve damage in diabetes. The trial is essential to our understanding of how diabetics should be treated in order to prevent the disabling complications of this disease. It is a costly trial involving perhaps $3- to $6 million annually for a number of years but it is absolutely necessary to put our treatment of diabetes on a sound scientific basis.

The potential benefits of diabetes research are tremendous, both in the reduction of human suffering and the improvement in the quality of life for patients with diabetes. For example, if general application of today's treatment advances could reduce new cases of diabetes-related blindness by 20 percent, there would be a savings to Federal agencies of at least $9 million a year in current disability payments and benefits. Reduction of all premature morbidity and mortality of diabetes by 20% would put $1.2 billion back into the economy. The risk of most diabetes-related complications associated with pregnancy alone can be significantly reduced today, potentially saving from $10,000 for each week of intensive care nursing for sick infants (or close to

$20 million annually) to $1 million for the lifetime care of each severely handicapped infant. Another modest and realistic goal today is a 10 percent reduction in amputations — saving $22 million a year in direct hospital costs, much of which is now paid by Federal agencies.

The President's FY 1984 Budget

The President's original FY 1984 budget will fund only 3674 new grants in FY 1984, a 30% reduction from the average number of new grants for the past 5 years (5200). Indirect and direct costs of the 3674 new and non-competing grants are estimated to be reduced by amounts that total about $154 million below what new and non-competing grants would ordinarily be funded at. Only about 9100 trainees are supported compared to the recent goal of 10,000.

The so-called March revision to the FY 1984 budget for NIH pretends to fund 5000 new grants without increasing the NIH budget. We have not been given the details on how an additional 1326 or so grants are to be funded but to do so would cost about $180 million, by our calculations. We understand that most of the ncessary $180 million will be obtained by significantly reducing or even eliminating many research center programs, drastically reducing the size of funded research grants, freezing trainee stipends for FY 1984, and reducing the DRR program drastically.

Each of these reductions is unacceptable. To fund 5000 new grants only at greatly reduced levels is not, in fact, to fund 5000 grants. To reduce the NIH research center program by about 20% to 30%, is to destabilize the research effort generally. There is no way to stretch the same 1.8% increase which would fund 3674 new grants into 5000 new grants without seriously crippling other important programs.

The ADA-NIH FY 1984 Budget Proposal

In the past two decades, the NIH has been remarkably successful in producing important scientific advances. For diabetes research in particular, the 5 years from 1977-1982 yielded extraordinary achievements. This was made possible by appropriations which increased by an average of about 12% annually. Only in FY 1982 was the NIH budget increase substantially less than the inflation rate.

An NIH budget increase of $487 million is the minimum required to meet several important objectives: the goal of 5000 new grants; plus an additional 400 new grants to enable about 35% of approved grants to be funded; 10,000 trainees could be funded with necessary stipend increases; indirect costs to universities and direct costs to investigators could be restored to appropriate levels, promising high-priority clinical trials could be funded; centers for research could continue at current program levels; and DRR could be funded at the level of increase originally estimated in the January budget.

This 12% increase will not be out of line with the other, non-NIH scientific research and development expenditures. The President's FY 1984 Budget for all Federal R&D programs proposes a 17% increase. The NSF, NASA and Energy Agency basic science budgets increase by 16%, with Defense Department R&D up by 29%. NIH-sponsored biomedical research programs should be treated as an equal partner in the Federal R&D effort, as it has been in the past. NIH research has, after all, contributed substantially to the well-being of our nation's citizens and economy.

- Each dollar invested in research has produced $13 in savings from benefits such as reduced costs and increased life expectancy.
- Health research discoveries commercially developed by private industry have returned more than $37 billion per year to the nation's economy.
- This return is 10 times the annual medical research budget and more than has been spent cumulatively on research over the past 40 years.

(The above information is from a 1982 analysis published by the American Association of Medical Colleges and other health organizations.)

Specific Institute Funding:

(a) Within the total NIH appropriation: An appropriation for NIADDK for FY 1984 of $475 million, a 15% increase over FY 1983 is recommended.

This increase is similar to the FY 1983 rate of increase. It will permit the Institute to support about 720 to 730 new research grants, less than the number of new research grants it supported during the period between 1979 and 1981. It will also enable the Institute to fund its fair share of the 10,000 trainees, or about 1,000. This amount will also provide for center research, and will enable the already-started Diabetes Control and Complications Trial, potentially one of the most important clinical trials ever, to continue. It would, finally, provide for a restoration of indirect and direct cost reductions and intramural reductions.

(b) Appropriations for NHLBI, NEI, NICHHD and NIA (Institutes with diabetes-related research) need to be substantially increased.

Much diabetes research is carried on at these Institutes. These Institutes must all receive a sufficient part of the 12% NIH increase we recommend to enable them to support their fair share of 5000 to 5400 grants at full cost, to continue centers programs at current program levels, and to support their share of 10,000 trainees with necessary stipends.

4. CENTER FOR DISEASE CONTROL, DIABETES CONTROL PROGRAM APPROPRIATIONS FOR FY 1984: $9 MILLION

The CDC has established Diabetes Control Program projects in 20 states. These programs are now yielding significant information in the important areas of community health care and education of diabetic people. They should be continued, and the information gained should be disseminated to other populations in states without such programs. A budget of $9 million is necessary for continuation of the existing programs, establishing mechanisms to translate these new approaches into other settings, and initiation of an innovative program designed to encourage patient care and education centers throughout the country. This is about $3 million above the current level.

STATEMENT OF JASON S. ROBERTS, VICE PRESIDENT FOR GOVERNMENT RELATIONS, JUVENILE DIABETES FOUNDATION

Senator WEICKER. Next we have Jason Roberts, vice president for Government relations of the Juvenile Diabetes Foundation.

Mr. ROBERTS. I won't go through all the things you've just heard. But I guess I can speak, Senator, being the father of a diabetic and hearing these great things that have occurred, and they've occurred basically because of what has been created by this Government.

You've offered me great hope. I sit here and I listen to Dr. Field and I listen to Chris Saudek, and it makes me feel good. Let's see if I can make you feel good. My son is being educated in your State.

Senator WEICKER. It also makes me feel good, because my brother's daughter is a juvenile diabetic so——

Mr. ROBERTS. We share a lot.

I heard Dr. Salans testify over in the House last week, and he said that we've learned more in the last 5 years than we've learned about diabetes all the years before. The promise is there. As a member of JDF and one who stands on street corners with cans to raise funds on our own, and I know how hard we work to do this, it doesn't hold a candle to what you have done for us. We sincerely appreciate it. We hope it will continue.

The budget that is currently proposed frightens us because we see all of this wonderful work falling apart. We see the centers diminishing. We need the centers certainly. We need all of those young people doing the research that has offered us such great hope and promise. And anything that I could say to the professionals would be second rate, really, because I could only speak basically as representing the 160 odd chapters that we, the JDF, have throughout the country.

And I really feel that the future for a diabetic is much brighter because of what this Government and the dollars they've put toward the research has done. And I for one would hate to see it diminished. I've got a stake in this situation, Senator. We all have, but I guess we share a more personal one. And we just don't want to see it diminish.

I can't add to what's here. The prepared statement that we've submitted for the record is fine. But really and truly, I really speak—I put all the stuff that I was prepared to say aside and I really speak from the heart, listening to those two people who were before me.

And I thank them and thank you for putting this effort together that will cure all of these kids and all of these other people that have diabetes. And I hope and pray that you just won't stop, that you'll fight this effort to cut, and you'll keep it going for us because I think the future is so much brighter now than what it was 10 years ago when we first got it in our family.

And again I can only thank you, and I think I can end here while the green light is still on. [Laughter.]

Senator WEICKER. Let me ask all of you that are here—maybe others can answer the question better than you can, Mr. Roberts. But I read an article recently in the Wall Street Journal which I believe related to your work at Johns Hopkins and a company somewhere in Minnesota that was also engaged in the same work of being able to implant mechanisms for the distribution of insulin in the system.

Now how much of that has come about by virtue of the Federal Government's effort, and when this is discovered, what's the benefit going to be in terms of the taxpayers rather than the benefit accruing solely, let's say, to the various companies that are involved in this?

I'd like to have a response to that.

Dr. SAUDEK. Mr. Chairman, I would say about that particular article, and how much has come about as a result of the Government funding, is that the best part of it has come about as a result of the Government funding.

The enterprise that we're involved with involves university funding through the NIH and NASA also, and to a small extent, development from industry, so it really is a triad that has I think worked out in a somewhat model way to allow NIH funding to seed work that will then be manufactured in the private sector.

Whether the private sector will ever make a profit I have no way of knowing. I'm not at all sure they will on the product. But the benefit for diabetics I think could be considerable. If these pumps could be made inexpensive, they will be implanted and so quite forgettable, it would be I think an advantage.

Senator WEICKER. I don't mean to be critical in any way of the pharmaceutical industry, the medical supply industry. But my only question arises when the benefit is arrived at principally by virtue of taxpayer dollars. You know, I'm not quite of a mind then to let the profits accrue to the private sector. I think there ought to be an equity, some benefit back to the public who I think was the one who put up the buck.

Dr. SAUDEK. Mr. Chairman, the NIH money that has come to me in this project and to our institution really is for research that is in fact necessary. In fact, the Metronic Co. that was written up in the Wall Street Journal has done this entirely on industry money, and I think done it considerably less well.

I think that the research that we're doing is open to the public, it's not only open to any one company. We have no agreement with this company to pass anything on directly to them. It's research that the NIH, with peer review, felt was important to be done and still is important to be funded.

Senator WEICKER. I think it is. I don't think there is any question about that. I just was wondering what happens when you finally get a device to the point where it can be used. Then what happens?

I gather from reading at least, and I don't want to get into specific companies, but insofar as the device being developed in Minnesota, it's not particularly cheap. When it gets marketed it's going to be rather expensive. And I imagine involved in that is a profit margin.

Now I was just wondering what would happen when you get your instrument ready here as to what is going to happen in terms of its availability to the public as a whole if indeed the research moneys have been provided in major portion by the public.

Dr. SAUDEK. I would say that the scientific research that led to the development of this has been provided by public money. I think that the actual manufacturing research and material research, the things that the manufacturers deal with has been their money.

I don't know of any specific payback capabilities. That's what you seem to imply and my——

Senator WEICKER. No; what I'm implying is that it seems to me that when you actually get the end product of your work and your colleagues' work, if indeed it's been funded by public moneys to a great extent, then it seems to me that that should be a far less expensive product on the market than that which has come solely through the private sector.

Dr. SAUDEK. Well, I——

Senator WEICKER. I don't know if that is going to happen or not. What I'm saying is, I do believe your endeavors are worthy, very worthy of continuing support by this Government. I have no problem with that at all, and I might add for many others in the room I feel the same way also. So I have no problem with that.

You're working on something very specific which can be of great benefit to many. But the economic factor certainly should not be a bar, it seems to me, as far as the public is concerned. If indeed the whole public is paying for this, then there should be some benefit to the whole public.

Dr. SAUDEK. I would support what you say and I certainly intend to see that whatever ends up as a byproduct of our research is going to be available to the whole public. I'll do what I can.

Senator WEICKER. Well, certainly it's interesting and something I think is well worth talking about at this juncture. I'm not saying there isn't a period of time still left, but the finish line is in sight, so far as what you're working on now.

I'm not going to put a time factor on that, but it's going to happen well within, I think, probably the next couple of years, at least the way I fathom it.

Dr. SAUDEK. I hope that will be true. And I appreciate your comments.

[CLERK'S NOTE.—Subsequent to the hearing the American Diabetes Association, through its Washington counsel, Richard Verville, supplied the subcommittee with the following information:]

LETTER FROM RICHARD E. VERVILLE, WASHINGTON COUNSEL, AMERICAN DIABETES ASSOCIATION

JULY 18, 1983.

The Hon. LOWELL P. WEICKER,
Chairman, Subcommittee on Labor, Health and Human Services, and Education, Committee on Appropriations, U.S. Senate, Washington, D.C.

DEAR MR. CHAIRMAN: This letter is being written on behalf of the American Diabetes Association.

As you will recall, during the public witness hearings on the NIH appropriation, you posed the question of whether private companies which participate in Government-funded research should have a special obligation to the public corresponding to the private rights and benefits obtained. In particular, you asked our witness, Dr. Saudek of Johns Hopkins, about the insulin pump experiment at Hopkins and the involvement of industry in it. This letter is a brief followup to state, for your information, some of the existing law related to industries' obligations in these circumstances.

In 1980, Congress passed Public Law 96-517, which eliminated inconsistencies among the Federal policies which then existed with regard to patent rights in Government-funded research. The legislation implemented a single, uniform national policy designed to "encourage private industry to utilize Government-funded inventions through the commitment of the risk capital necessary to develop such inventions to the point of commercial application," H.R. Report No. 96-1307, 96th Congress, 2d session, part I, 6460 (1982). The legislation established a presumption that ownership of all patent rights in Government-funded research would vest in any contractor that is a nonprofit research institution or small business. That presumption is rebuttable, however, in situations where the funding agreement is for the operation of a Government-owned research or production facility, where exceptional circumstances warrant restrictions on the company's right to take title to the invention, or where national security considerations justify retention of title by the Government. Public Law 96-517, section 6(9), 35 United States Code and 202(a).

On February 19, 1983, President Reagan issued a statement on patent policy which extended the presumption set forth in Public Law 96-517 to all of private industry. This, in effect, means that absent the presence of any of the exceptions described in the preceding paragraph, patent rights will generally accrue to the private company which develops an invention during the course of Government-funded research activities. This is intended as an incentive to the provision of risk capital.

The statute and regulations impose certain provisions which are intended to temper the undesirable aspects of this pro-industry policy. Agencies have the right to receive periodic reports from the contractor on utilization of inventions. If patent rights are not pursued aggressively, they are waived. Further, the Government retains "march-in rights" which enable the Federal agency, under whose funding agreement the invention was made, to require that the contractor grant licenses in any field of use. "March-in" rights may be invoked where the patent owner has failed to achieve practical applications of the subject invention, where the action is necessary to alleviate health or safety needs, or where requirements for public use are not being met. 35 United States Code, section 2303. They could be used, it seems, to expand the number of licensees.

The public obligation of the patent holding business essentially is to develop the product and apply it and to license it where appropriate public use is not made without such licenses. There is no obligation related to the price charged for the product when sold, nor to the royalties charged for licenses; such royalties ordinarily fund their way into the price also.

Also, the commitment of private risk capital which the patent right legislation was intended to encourage is generally recouped in the price of the product so it is not necessarily of public economic benefit. Of course, if the capital commitment is substantial and if the product is never marketed, there is a real loss to the investor. Whether the capital contributed is substantial is negotiable, it would seem.

If one wanted to require favorable pricing by companies that have benefited from Government research, new legislative authority would seem to be necessary. It is possible that the funding agency could exercise some influence over this matter as part of its selection of contractors, however. Perhaps there should be some affirmative obligations that the agency should insist on related to the pricing and accessibility of the product.

I hope that you will find this condensed explanation of the status of current law governing the disposition of patent rights to be responsive to your question. Please understand that the above description is not intended to be suggestive of any position taken by the American Diabetes Association with regard to patent issues.

Sincerely,

RICHARD E. VERVILLE,
Washington Counsel.

PREPARED STATEMENT

Senator WEICKER. Mr. Roberts, thank you very much.

Mr. ROBERTS. Thank you, Senator.

[The statement follows:]

Statement of Jason S. Roberts

I am Jason Roberts, Vice-President for Government Relations of the Juvenile Diabetes Foundation. JDF is an international voluntary health organization dedicated to supporting and furthering research and education in diabetes; to this end, we have funded $18.4 million in diabetes research, training, and education activities over the past decade. Today, I appear before you on behalf of our Board of Directors and entire membership and their families in over 154 chapters throughout the United States.

You are among the distinguished colleagues who have made the appropriations decisions in recent years that have created a new horizon for our children. We can now live each day with a little less fear that our children will become blind, suffer heart disease, be afflicted with neuorological disorders, or be sustained only by a kidney dialysis machine. We are indebted to you because you heard our call and responded by providing the leadership and fiscal support for a comprehensive diabetes research, training, prevention, education and control program -- a program which has become a model of governmental effectiveness and efficiency. Your generous dollars have been targeted, focused on only the highest quality research, and have been administered by some of the finest, most innovative and compassionate public officials ever to serve in government.

The mechanism for continuing the Federal onslaught on diabetes is in place: research is conducted in practically every NIH institute. There are seven diabetes research and training centers and four diabetes-endocrinology research centers in operation. The Diabetes Data Group and the Diabetes Information Clearinghouse are performing the functions that you mandated. The Centers for Disease Control and 20 State health departments are jointly conducting a wide range of activities to improve the quality of life for the person with diabetes and reduce morbidity, mortality, and the costs of diabetes and its complications. Recognizing that diabetes afflicts almost 50% of adults in some Indian tribes, the Indian Health Service is implementing a Model Diabetes Health Care Program to develop and evaluate effective and culturally acceptable methods to reduce the severity of the disease and its costs. The Diabetes Mellitus Interagency Coordinating Committee, which consists of representatives from 24 units of the Federal government with responsibility for diabetes-related activites, recently organized an important Conference on the Prevention and Management of Five Complications of Diabetes. The National Diabetes Advisory Board, a body of government officials, health care professionals, and consumer-advocates for the diabetic, provides a coordinated focus for the plethora of Federal diabetes-related activities.

THE SUCCESS OF THE DIABETES PROGRAM

These programs are the spokes of the wheel. The hub of our program, and the activity which gives us hope for our children's future is RESEARCH. This Committee has responded generously to our pleas for NIH support during the past decade. What have these precious dollars bought? Has your investment produced substantial dividends? Can we point to successes in the treatment of this Nation's diabetics? Do we have a reasonable basis for being optimistic about a cure for our children and prevention of diabetes in all of our children? The answer is a resounding YES -- in terms of prevention, treatment, and potential cure.

* Researchers have demonstrated that several common human viruses are capable of producing diabetes in laboratory animals, thereby possibly leading to the development of a preventive diabetes vaccine.

* Scientists have identified genetic markers for diabetes which may make it possible to identify high-risk candidates before they develop diabetes and its complications.

* Researchers have determined that there is a causal relationship between lack of control (fluctuation in blood sugar levels) and onset of diabetes' complications; a vital clinical trial, supported by NIADDK and other NIH institutes, may demonstrate whether adequate control will allow us to prevent, or mitigate, the devastating and debilitating complications once the person has the disease.

* Scientists have demonstrated that meticulous control of blood sugar of the mother and monitoring of the fetus can reduce most of the complications of a diabetic pregnancy to a rate comparable to those in non-diabetic pregnancies.

* Clinical studies have established that photocoagulation significantly reduces the risk of blindness for proliferative diabetic retinopathy.

* Scientists have developed a miniature battery-powered pump, worn externally, which feeds a continuous supply of insulin to the diabetic; with this device, insulin injections are not necessary and diabetics can maintain almost normal blood sugar levels.

* Researchers have produced human insulin through recombinant DNA -- insulin which has been approved this year for use by the Food and Drug Administration -- which will ultimately provide an unlimited supply of cheaper, purer, and more compatible insulin.

* Scientists have developed new tests and techniques to monitor blood sugar control more accurately than ever, and in the home, where health costs can be confined.

* Scientists have successfully transplanted insulin-producing cells from one animal species to another without immune rejection, thereby producing a return to normalcy in previously diabetic animals.

* Researchers have developed new techniques and drugs which suppress the rejection process in transplantation; this development, like so many other diabetes breakthroughs, will benefit millions of Americans with non-diabetes-related health problems.

With this good news -- developments which have resulted directly from your support of diabetes research at NIH -- we cannot permit ourselves to live with a false sense of security. Diabetes remains the third leading cause of death in the United States. It afflicts ten million Americans, claiming 300,000 lives annually -- almost 1,000 lives every day -- and this number is increasing.

* It is the leading cause of new blindness in the United States.

* Diabetes causes almost 50% of amputations of the foot and leg among adults.

* Diabetes causes severe neurological disorders.

* Infants born to mothers with diabetes experience a disproportionately high rate of mortality, congenital malformations, respiratory distress, prematurity, and other serious medical problems.

* Diabetes is one of the four major risk factors for cardiovascular disease.

* Diabetes is responsible for 20% - 25% of all cases of kidney failure. The Federal government spends over $400 million per year supporting diabetics on dialysis machines -- two and one-half times NIH's allocation for research to eliminate this insidious disease once and for all.

While we have hope for the future, we are terrified by the prospects for today. We have read the newspaper accounts and have reviewed the Administration's budget request.

The Administration has proposed for 1984 a budget request of $4.07 billion, a meager 1.8% increase over 1983 levels. Adoption of this budget would result in:

* A 30% reduction in the number of new and competing research grants. About 3,676 grants could be funded, compared to 5,109 in 1981 and 6,543 in 1979.

* A severe reduction in the percentage of approved grants which would receive funding, from 39% in 1981 to 23% in 1984.

* A substantial decrease in payline (cut-off score) for funding research grants, from 242 in 1979 and 219 in 1980 to 165 in 1984.

* Reductions in the direct costs of research grants. In order to bring the number of grants to even the paltry level of 3,676, each NIH institute is forced to reduce the dollar size of grants by arbitrary percentages ranging from 4% to 8%. The integrity and quality of research may be adversely affected by this approach to funding.

In recent weeks, it appears that the Administration has begun to share our concern about the depletion of research grant support. However, rather than enlarge the overall source of funds available to NIH, the Administration is proposing to simply reallocate funds among institutes and among program mechanisms. Apparently, the revised budget would permit support of about 5,000 research grants. However, it would "rob Peter to pay Paul" by eliminating funding for all centers -- including the diabetes research and training center at Vanderbilt University and the diabetes-endocrinology research center at the University of Iowa -- which are subject to funding renewal. The revised proposal would eliminate the budgeted stipend increase for research training, providing yet another disincentive for young M.D.'s and PH.D.'s to pursue research careers. It would also further reduce the direct costs of those grants which do get funded.

Mr. Chairman, the biomedical research community and its beneficiaries -- our children -- are being subjected to a "shell game," a simple jockeying of funds from one mechanism to another.

Research grants remain our number one priority!!! But the strength of the NIH effort is its program balance -- grants for basic research; training awards to ensure a supply of vigorous young minds in research in the years ahead; centers to provide the integrated forum for research, education of health care professionals and patients, and practical application of research results to patient care; clinical trials; and intramural research conducted by the great researchers who have assembled under NIH's roof.

JDF's Funding Recommendation for NIH

Diabetes is a devastating disease which invades virtually every body system: the heart, the circulatory system, the eyes, the kidneys, and the senses. Accordingly, virtually every NIH institute provides support for diabetes research. Accordingly, our recommendations provide for reasonable increases in the funding of all NIH institutes and provide for the program balance that has been lost in recent years.

We respectfully recommend that Congress appropriate an increase of $487 million over the FY 1983 level of funding for the National Institutes of Health. This 12% increase would enable all basic NIH programs to be continued at levels consistent with 1983 and would provide for modest but badly needed real growth. Our detailed institute-by-institute appropriations recommendations are appended to this testimony. Our proposed increase, $414 million over the Administration's budget, would provide for the following:

* NIH would be able to support slightly over 5,000 new and competing research grants. There is nothing magic about the number 5,000, except that it was originally proposed as a minimum of grants required to ensure a strong and stable research effort. This proposal would enable NIH to fund about 35% of all approved research grants.

* NIH could support approximately 10,000 research trainees, about the average number of the past five years. As an individual whose child has diabetes, I live with the profound fear that today's research advances will not be translated into a cure for lack of qualified investigators to conduct the necessary research. We are dedicated to the proposition that we must foster a climate in which today's scientists, physicians, and indeed, medical students, will seek out careers in health research.

* NIH could restore direct and indirect cost reductions in all programs. As mentioned, NIH directors have been forced to play a "shell game," i.e., cut funds from all research grants in order to fund more grants. It is important to recognize that full funding of direct costs does not represent a "windfall" to the clinical investigator. His or her research grant application has been reviewed, for quality and cost, by a rigorous peer review mechanism.

* NIH could modestly expand its research centers programs, contracts, intramural research, new clinical trials and manpower training awards programs.

The CDC centers program has been severely hampered since its inception because of inadequate funds to fully support the intervention projects which have demonstrated their cost-effectiveness. We concur with the recommendation of the National Diabetes Advisory Board that Congress appropriate $9 million for CDC's National Diabetes Control Program in FY 1984. These funds would enable CDC to maintain the current effort, expand the program to five additional states, provide start-up costs for new or upgraded community patient education services, and implement one or two community-wide programs in which the knowledge gained from all of the individual state projects can be integrated into a total effort to affect all diabetes-related health care issues in that community.

Diabetes is a critical health problem among American Indians, affecting almost 50% of adults in some tribes. Congress authorized several years ago an Indian Health Service Model Diabetes Health Care Program to develop and evaluate effective and culturally acceptable methods to reduce the severity of the disease and to reduce the expense to the Indian Health Service of related medical services. In New Mexico, diabetes-related hospitalizations have decreased 30% among residents of American Indian communities served by the Albuquerque project. We concur with the National Diabetes Advisory Board's recommendation that Congress provide $1.9 million in FY 1984 for the Indian Health Service to operate the five Model Diabetes Core programs and to expand training and information dissemination activities to other service units.

Within the next decade, we pray that we at JDF will be able to write the book on how diabetes was cured and the book will be dedicated to you, the Members of this Committee, who had the vision and patience to ignore what might have been politically expedient and to do what you knew in your hearts was right.

Thank you for your attention.

JUVENILE DIABETES FOUNDATION

FY 1984
APPROPRIATIONS RECOMMENDATIONS
(in millions of $)

NATIONAL INSTITUTES OF HEALTH INSTITUTE	FY 1983 (Diab. $)	Admin. 1984	JDF 1984
National Institute of Arthritis, Diabetes, Digestive and Kidney Diseases	412.2 (83.4)	419.6	496
National Heart, Lung, and Blood Institute	622.7 (16.5)	628.0	704
National Eye Institute	141.6 (20.8)	143.3	169
National Institute of Child Health and Human Development	253.6 (9.7)	257.3	284
National Institute of Neurological and Communicative Disorders and Stroke	295.7 (6.1)	301.0	331
National Institute of Allergy and Infectious Diseases	273.6 (4.9)	281.4	307
National Institute of Aging	94.1 (2.3)	95.7	105
National Institute of Dental Research	78.9 (2.2)	80.6	88
National Institute of General Medical Sciences	369.6 (1.3)	374.8	396
National Institute of Environmental Health Sciences	164.4 (.1)	166.7	180
Division of Research Resources	213.8 (17.7)	228.5	240
Other			1,265
TOTAL NIH	4,004 (165)	4,077	4,491*
CENTERS FOR DISEASE CONTROL Diabetes Control Projects	6.0	6.0	9.0
INDIAN HEALTH SERVICE Control Projects	1.4	.9	1.9

*Appropriations at this level would result in an increase of approximately 15% in diabetes research.

STATEMENT OF DR. RICHARD FREEMAN, PRESIDENT, RENAL PHYSICIANS ASSOCIATION

Senator WEICKER. Dr. Richard Freeman, president of the Renal Physicians Association.

Dr. FREEMAN. Good morning, Mr. Chairman.

Senator WEICKER. Good morning.

Dr. FREEMAN. Thank you very much for the opportunity to testify. Since I'm the only renal-oriented individual I'm officially speaking for the Renal Physicians Association, but I also belong to and have offices in the American Society of Biology and the American Association of Artificial Internal Organs, the International Society of Biology, and too many others.

So I would like to emphasize the importance of research in kidney diseases.

The Renal Physicians Association, together with other nephrologists, perhaps better than any other group, recognize the realities of the fiscal climate. It is our strong contention that improvement in patient care and the reduction in treatment costs can only be achieved by research and the training of new individuals who will provide the continuum of the search for new knowledge.

Whatever the perception of Congress may have been of past performance of the NIH in the kidney research program, the new leaders of the NIH have the unconditional support of this organization because we know them as established scientists and efficient administrators, and individuals of demonstrated integrity.

Very few diseases of the kidney are solved by simple, singular discoveries. Breakthroughs are not the result of a solitary investigator's work. Thus, we contend that investigations continue on the broad front of physiology of the kidney, pathology, immunology, circulatory problems, infections, and dialysis.

Specifically, the RPA urges Congress to consider and adopt the following recommendations:

One, provide support to the NIADDK in amounts sufficient to increase the numbers of individual research grant awards at full costs, as recommended by the scientific study section. Academicians have become discouraged about the uncertainties of funding. I know this very well personally. This is a serious disincentive to young investigators to continue in the search for new knowledge. These are the people on whom our future hopes are based.

Two, we support an increase in research to M.D.'s for biomedical research. Only 23 percent of R–O1 grants from NIH go to M.D.'s at the present time.

Three, increase center awards. Despite an overall increase of 12 percent in the 1983 NIADDK budget, a decrease of 8.5 percent in center grants will be necessary. The proposed 1984 budget will stop funding of centers in order to maintain the support at the current level of 5,000 individual investigator awards, and this is with an 11-percent decrease in the latter. Center grants insure that institutional memory will not be lost as individual investigators move to other institutions or leave the academic world.

Four, we recommend that established national guidelines be created for indirect institutional costs. This avoids the competition between investigators and their institutions.

Five, we recommend a central study section for clinical research as compared with basic research.

Six, we support multiple investigator investigations for nutrition studies. The importance of nutrition in patients with kidney diseases has been known since the 19th century. There will be no significant savings to the ESRD program from demonstration projects. It is now time to examine the facets of individual nutrients as they apply to the progression of kidney diseases or the manner in which complications occur.

Seven, we recommend continuation of research career development awards.

Eight, we recommend deemphasis of investigation in hardware for dialysis.

Nine, we recommend that monitoring of the ESRD program is not in the purview of the NIH but, rather, HCFA.

Ten, we urge increased support for investigations in factors that determine the outcome of transplantation.

Eleven, the RPA does not favor the establishment of a separate arthritis institute.

Twelve, we recommend the establishment of a National Advisory Board for the kidney-urology program.

One treatment program, the ESRD medicare program, keeps 70,000 patients alive at a cost of $1.8 billion. It is our contention that it is not realistic nor morally acceptable to deny therapy to these people or to develop a two-tiered system of therapy for these end-stage renal disease patients.

The NIADDK kidney-urology program is the single most important source for investigations which will eventually decrease the burden of expensive care. An additional $10 million to kidney-urology and $53 million to NIADDK is necessary simply to maintain the program in the fiscal year 1984. Obviously more is necessary.

We urge Congress to consider the NIH as the pivotal institution that will lead the way to solutions to problems for which there are no answers today.

Thank you.

PREPARED STATEMENT

Senator WEICKER. Thank you very much, Dr. Freeman. I appreciate it.

[The statement follows:]

STATEMENT OF DR. RICHARD FREEMAN

The Renal Physicians Association (RPA) is a national organization of academic and practicing physicians that has as its goals enhancement of research in diseases of the kidney as well as education and quality patient care for patients who suffer from disorders of the kidney.

The staggering costs of the treatment of patients with diseases of the kidney has been a difficult and perplexing problem for the Congress and Administration. It is the strong contention of the RPA that improved patient care, quality of life and reduction in treatment costs can only be achieved by research and training of individuals who will provide the continuum of the search for new knowledge.

Historically, the manner in which NIH supported research in kidney and urologic diseases may not have been optimal. However, we are impressed with the new leadership of the NIH and the NIADDK, their vigor, attention to detail, methods of encouraging quality research and logical assignment of priorities. Whatever the perception that Congress may have had of past performance of the NIADDK, the new leaders have the unconditional support of this organization because they are known to us as established scientists, efficient administrators and individuals with a genuine grasp of the state of the art as well as demonstrated integrity.

The RPA, perhaps better than any other group, recognizes the reality of the fiscal climate, but we contend that the only realistic mechanism to avoid the agonies of withholding life-saving therapies, develop means of prevention of renal failure and reduce mortality and morbidity is through research. New windows are opening on reasons why individuals are stricken with glomerulonephritis, the most common cause of end-stage renal disease; why diseases of the kidney progress despite the removal of the trigger event; factors that improve transplantation success; and how basic functions of the kidney affect diseases of other organ systems.

Very few diseases of the kidney are solved by major singular discoveries. Rather, bits and pieces of knowledge are synthesized in a progressive fashion which will lead to a higher success of treatment and a greater understanding of disease processes that allow effective intervention in the course of the disorder. Thus, we contend that investigation continue on the broad front of physiology of the kidney, pathology, immunology, circulatory problems, infections and dialysis.

Specifically, the RPA urges Congress to adopt the following recommendations:

1) Provide support to the NIADDK in amounts sufficient to increase the numbers of individual research grant awards. Academicians in the field have become discouraged when projects are reviewed, approved, given high priority ratings but fail to receive funds. Eventually this leads to contraction of the top level investigator population because they simply give up. They give up because of unknowns of future support, instability of the entire intrastructure of academic medicine which has come to depend on government aid, the increasing pressures of administrative activities and the inability to cope with personal financial commitments in an age where demands on personal income are escalating. College tuition for academician children is but one item in a long list that may preclude a talented individual from entering or continuing in the academic and investigative role. This set of circumstances is a serious disincentive for young academicians to continue in the pursuit of new knowledge. These are the individuals on which our future hopes are based.

2) Reverse the trend of support going to non M.D.s for biomedical research. Only 23% of R01 grants from NIH go to MDs.

3) Increase center awards. This will insure that institutional memory will be perpetuated and not lost as individual investigators move from one institution to another or leave academic careers.

Despite an overall increase of 12% in the NIADDK budget, a decrease of 8.5% in center grants will be necessary for fiscal year 1984.

4) Establish national guidelines for institutional indirect costs so that negotiations need not be made on an individual institutional basis and some control can be maintained over the competition between the investigator and his or her own institution for federal dollars.

5) Establish a central NIADDK study section for clinical research utilizing the same peer review system in effect currently but directed toward research on patients with diseases of the kidney. Unless there is a serious misunderstanding in our society, the work of medical investigators should eventually be applied to people. Those in the best position to judge the relevance of individual research activities are professionals who have been trained and continue to have experience with patients in need.

6) Provide support for individual investigators for nutrition studies. The role of nutrition in patients with diseases of the kidney is, and never has required demonstrations that it is an important ingredient in the management of patients with diseases of the kidney. It is now time to examine the facets of aberrations in the utilization of individual nutrients as they relate to the progression of kidney diseases or the manner in which complications occur in patients with kidney disease. It is our strong recommendation that awards in this category be made to multiple centers or individual investigators in amounts of less than $100,000 each with emphasis on human investigation as opposed to emphasis on animal studies.

7) Continue and increase Research Career Development Awards, a necessary step to stabilize the structure of the academic research community.

8) The NIADDK should deemphasize investigations in hardware for the treatment of patients with end-stage renal disease. Industry has developed to the degree that research and development funds should be gained from that source rather than federal funds. The new popular treatment, chronic ambulatory peritoneal dialysis (CAPD) would fall into this category.

9) It is the opinion of the RPA that the monitoring of the national ESRD program is not in the purview of the NIH. It is our opinion this is the responsibility of the Health Care Financing Administration which supports the clinical care of these patients. Though an efficient national information system on the ESRD program, or any facet of it is critical, the responsibility should be with those who support the treatment program and not the National Institutes of Health.

10) The association urges that increased support be available to investigations in factors that determine the outcome of transplantation. This modality of therapy offers the most expedient method of removing the growing numbers of patients requiring repetitive expensive dialysis therapy. This is assumed that therapy will continue to be offered to all those in need.

11) The RPA does not favor the establishment of a separate arthritis institute since this will duplicate NIH administrative responsibilities. Further, there is significant overlap in areas of investigation such that in-house communications and activities should continue to be coordinated.

12) The RPA favors the establishment of a National Advisory Board for the Kidney-Urology Program as proposed in previous legislation. Input from investigators, practitioners, consumers and others in the field is critical to maintain perspective on deficiencies that need to be addressed by deliberate prospective research. We also favor the establishment of a National Clearing House that receives and collates all activities from all disciplines involved in kidney research. This should enhance communication and avoid unnecessary duplication of parallel activities.

One single treatment program, The Medicare Dialysis and Transplant Program supports life for 70,000 patients at a cost of $1.5 billion dollars which is 4% of all Medicare expenditures and 10% of Part B Medicare expenditures. An increase in the investment of research and development funds in the broad front of kidney and urologic diseases is the only logical and ethical method of reducing these costs over the long-run. It is not realistic or acceptable to deny therapy or develop a two-tiered system of therapy in the opinion of this association. The investment of an additional 10 million dollars for Kidney and Urology and 53 million dollars for the NIADDK is necessary simply to maintain the program at the same level in fiscal year 1984.

The social and ethical problems of medical care in the United States will not become less complex. The Kidney-Urology program is the single most important source for investigations which will result in a decrease in the burden of expensive care in the future. The RPA urges the Congress to consider the NIH as the pivotal institution that can lead the way to solutions to problems for which there are no satisfactory answers at present. We urge that the Congress support the Institutes so that meaningful answers can be found for next year, the next decade and for our successors and children.

STATEMENT OF DR. PAUL SHERLOCK, CHAIRMAN, NATIONAL DIGESTIVE DISEASES ADVISORY BOARD

Senator Weicker. Dr. Paul Sherlock, chairman of the National Digestive Diseases Advisory Board.

Dr. Sherlock. Mr. Chairman, I am Paul Sherlock, chairman of the department of medicine of the Memorial Sloan-Kettering Cancer Center and professor of medicine at Cornell University Medical College. I speak to you today as chairman of the National Digestive Diseases Advisory Board.

All of the board members and members of our digestive disease community are most grateful to you and to your colleagues for your continued support of biomedical research. However, we hope that you share with the board our concern about the adverse impact of the proposed fiscal year 1984 budget on the implementation of the national plan to combat digestive diseases, as reported to Congress by the National Commission on Digestive Diseases, and updated by our advisory board recently. It is our opinion that the proposed 1984 budget will have a major damaging effect upon digestive disease research as proposed by this plan.

The major recommendations of this plan were:

One, to increase budgetary appropriations for digestive disease research, including digestive disease centers.

Two, to establish a data collecting program.

Three, to establish an educational clearinghouse.

Unfortunately, despite the recommendations in the plan, and despite the growth of interest of investigators in the field, there has been no real growth in budgetary allocations for digestive disease research since 1975. During this period, the number of approved applications for research grants grew by over 100 percent. However, the number actually funded remained about the same.

The continued lack of budgetary support for growth in digestive disease research is a major cause of concern by our advisory board, especially in light of some of the new promising opportunities in digestive diseases.

Some of these opportunities will be outlined by subsequent speakers this morning, and has been addressed by my written testimony.

For the proposed fiscal year 1984 budget, inflationary and increased costs associated with research or with research grants necessitate a number of drastic actions to maintain research activity in the NIADDK. The proposed budget is bound to have a significant adverse effect on young investigators, as was pointed out by the last speaker, about to enter the field, as well as on established investigators.

The advisory board has carefully reviewed the experience of the arthritis and diabetes boards with their center programs. It has concluded that certain research problems and opportunities in digestive diseases may best be addressed by a variety of experts, working together in basic and clincial sciences, in the context of a center.

The board is concerned to learn that the proposed administration budget eliminates all new center grants and, hence, does not provide the opportunity for the initiation of a digestive disease centers program.

The board strongly recommends that funds be allocated to digestive diseases and specifically for the development and establishment of a digestive disease center program. As for the pending authorizing legislation, the board recommends $8 million in fiscal year 1984 for this purpose.

The board also recommends that a digestive disease data system be established. The continuation of the National Digestive Disease Clearinghouse is also recommended, and funding for those two latter programs is recommended as per the pending authorizing legislation at $1 million in fiscal year 1984.

In order to restore the proposed reduction in new and competing research grants, restore a centers program in the NIADDK, and restore funds for intramural research, the Board also supports appropriations of approximately $475 million for the NIADDK.

Mr. Chairman, we appreciate every effort that this subcommittee has made in the past through legislation to assure that the health of this Nation is secured.

Thank you for the privilege to appear before you, and I'm happy to answer any questions on this.

Senator WEICKER. Thank you.

Both you and Dr. Freeman, and maybe there are others, have raised the issue of discouraging those going into research with this kind of a roller-coaster type of funding.

Is it your feeling that this type of a situation that confronts us now is going to impact in the out-years what we're going to have available to us in the way of experience?

Dr. SHERLOCK. Yes; there's no question about that. Some of our young people in the digestive disease field, and I'm sure in other fields as well, see what's been happening to the research grants in terms of the cuts and also the priority scores, and the difficulties in obtaining research grants. And they see very meritorious research grants that have been approved by study sections just not quite making the priority score and, therefore, not being funded. And they get very discouraged.

This is happening with established investigators, and they realize that maybe it is better to go out and to practice and not to worry about this. And obviously over the years we will lose some of the opportunities that are occurring at the present time to advance the research that is going on in the field.

So I definitely feel it will have an adverse impact down the line. Initially it may not be felt so much, but down the line it will be felt quite severely.

Senator WEICKER. You know, I think it's really up to you and others who are here in this room and others in your profession to point out, that whatever dollar savings are achieved budgetarily in fiscal year 1984, or fiscal year 1983, which we're in, the real price to be paid from that is in the out-years.

Dr. SHERLOCK. And we're all concerned about it.

Senator WEICKER. You see, the politicians feel that by that time they'll have tiptoed off the stage and——

Dr. SHERLOCK. And they don't have to worry.

Senator WEICKER [continuing]. They don't have to worry about it. And unfortunately, as you well know, Doctor, there's no quick way to make up the lost ground in your field or the fields of those representatives.

Dr. SHERLOCK. Absolutely. Some of these would represent lost opportunities.

PREPARED STATEMENT

Senator WEICKER. Thank you very much.

Dr. SHERLOCK. Thank you.

[The statement follows:]

STATEMENT OF DR. PAUL SHERLOCK

Mr. Chairman, I am Paul Sherlock, Chairman of the National Digestive Diseases Advisory Board. I am also Chairman of the Department of Medicine at Memorial Sloan-Kettering Cancer Center and Professor of Medicine at Cornell University Medical College. I speak to you today representing the National Digestive Diseases Advisory Board. All of the Board members and members of the digestive diseases field are most grateful to you and your colleagues for your continued support of biomedical research. However, we hope that you share with the Board our concern about the adverse impact of the proposed budget in 1984 on the progress on digestive disease research and on the implementation of the National Plan to Combat Digestive Diseases. It is our opinion that the proposed budget will have a major damaging effect.

In 1974 and 1975 Congress increased financial support to research in digestive diseases in response to a national conference which demonstrated the importance of digestive diseases as a national health problem. As a result of that support, there was an increase in the number of grants funded in digestive diseases. Since then there has been a yearly increase in the number of applications for new research grants reflecting a true growth of interest in the field.

In recognition of the growing importance of digestive diseases as a health problem Congress also added the name "Digestive Diseases" to an Institute, and called for the appointment of an Associate Director for Digestive Diseases. Further, in 1976 Congress established the National Commission on Digestive Diseases. In 1979 this Commission submitted a National Plan to Congress for this important group of diseases.

In its 1979 report to Congress, the National Commission on Digestive Diseases stated that;

"Digestive Diseases constitute the third largest component of the total economic burden of illness in the United States, being outranked only by circulatory diseases and by the combined category of accidents, poisonings and violence."

The Commission made an intensive study and provided an extensive report on opportunities for research in digestive diseases.

The major recommendations of this Commission were: (1) to increase budgetary appropriations for digestive diseases research including multi-disciplinary Digestive Disease Centers, and (2) to establish data collecting groups to provide information on the incidence, prevalence, clinical course, and economic burden of these disorders and an educational clearinghouse, to increase public awareness and to provide information to patients and families regarding digestive diseases.

Unfortunately, despite the recommendations of the Commission, and despite the growth of interest of investigators in the field, there has been no real growth in budgetary allocations for digestive diseases research since 1975. There has been some increase in dollar amount over this over this time, but when budgetary allocations are adjusted either for the annual rate of inflation or for the biomedical research and development price index, there is no increase in constant dollars. This continued lack of bugetary support for growth in digestive diseases research is a major cause for concern by the Board, especially in the light of some of the new promising opportunities for the prevention, treatment, and early diagnoses of these disabling disorders. These opportunities come from research advances made by NIH supported researchers. Some of the significant advances include:

1. The survival rate in liver transplantation has been greatly increased by improvements in management and surgery, and by use of a new immunosuppressant, cyclosporin A, to control the body's tendency to reject the graft.
2. Nine new peptide hormones have been discovered in the gut in the past few years. We can study how to modify their effects

and perhaps block the hormone's attachment to the cell they influence by an inert analog, and thus prevent the stimulation of secretion in the digestive tract when that is not desireable.

3. Some peptide hormones have been found in the brain as well as in the gut. New knowledge in this area may provide insights into the interaction between the central nervous system and digestive system.

4. Endoscopic techniques for research are being developed. It may be possible to evaluate circulation in the gut wall _in vivo_ by laser doppler effects and wash out techniques. Devices are being developed to: catheterize tortuous ducts with a toposcopic catheter propelled by fluid injected into its lumen, and to obtain continuous readings on pH, CO_2 and other parameters of secretions in ducts using a flexible probe with lighting and readout conducted through flexible fiberglass conduits. This should make possible the _in vivo_ studies of changes in secretions under physiological conditions and in response to drugs.

5. Gastrointestinal bleeding accounts for at least 150,000 hospital admissions each year. It is now possible to identify the site of bleeding through an endoscope in most patients who are bleeding from the upper gastrointestinal tract. In some of these cases, the bleeding site can be treated locally through the endoscope and the bleeding stopped, and thus abdominal surgery can be avoided. However, the safety and efficacy of the procedure must be determined by a carefully controlled clinical trial.

6. About a quarter of gallstones contain primarily calcium and pigment, rather than cholesterol. The characterization of the components and their interrelationships should provide a basis for understanding the pathogenesis of these stones and means of treatment and prevention.

With such advances as these, there is now the opportunity to understand, clarify, and to bring effective clinical treatment to many Americans suffering from diseases of the digestive tract.

In addition to the identification of research advances and opportunities, the Board through its sub-committees is involved in the development of an algorithm using decision theory as applied to medical practice. This project is directed to reducing the costs associated with the medical surveillance of patients who because they have precancerous conditions are at risk of developing cancer of the colon.

The Board in cooperation with HCFA is also developing data concerned with establishing the incidence, prevalence, and costs associated with diseases of the digestive tract. The Board is also significantly involved with the development of a National Digestive Diseases Education Program. This program will utilize the resources of the private sector, voluntary health organizations, and government agencies to support a coordinated patient information and education health care program for digestive diseases for the public and health care professional. The results of these projects will be made available to you, members of your Committee, and to other members of Congress as part of the Second Annual Report of the Board.

Mr. Chairman, I wish now to discuss some of the budgetary facts concerning research activity in digestive diseases. The FY 84 budget proposed by the administration provides for a slight increase in total funding for NIADDK over the FY 83 funding level. Because of inflation and the increased costs associated with research grants a number of drastic actions will be necessary to maintain research grant activity in NIADDK. Based on past experience the NIADDK anticipates that in FY 84 there will be about 300 new applications for new and competing regular research grants in digestive diseases. The number that will actually be funded is estimated to be less than 100. Only grants which receive a priority score of 180 or lower will be funded (the lower the score, the more meritorious the grant). The costs of all NIADDK new research grants will be cut by 11% in direct costs and 10% in indirect costs. New centers grants will be completely eliminated in all NIADDK areas, and no new contract funds will allocated. It is also proposed that non-competing grants be cut by 4.6% in direct costs and 10% in indirect costs. These cuts are in addition to those normally suggested by the scientific study section which reviews a grant application for scientific merit. Those who have entered the field will face discouragement in light of this proposed budget and in spite of Congress's previous successful efforts to stimulate research in digestive diseases, the number of new digestive disease research applications will certainly begin to fall off.

The Board recommends that increased funds be specifically designated for digestive diseases research. Otherwise, we believe that some established investigators will abandon their research efforts, and research teams which often have been developed over decades of effort and developed with Congressional support will be dissolved. When this occurs to established investigators talented new digestive disease investigators may decide not to pursue a career in research. Thus, the successful efforts to develop interest in this important field will be lost. With the withdrawal of prospective investigators it may take an entire generation to redevelop teams of investigators with the skills, interest, and resources required to conduct research in digestive diseases. This is particularly unfortunate since recent advances in sophisticated technologies that are so vital to the study of complex problems of digestive diseases now make it possible to pursue exciting opportunities which can lead to the prevention, cure, and to early diagnoses of digestive disorders. Thus, the long term consequences for health research manpower in the digestive diseases area are alarming.

The Board in its brief period of existence quickly realized that the National Plan to Combat Digestive Diseases as outlined in the Digestive Diseases Commission report to Congress needed immediate attention and specific budgetary action. The Board has the responsibility to advise Congress that the proposed budget for FY 84 will have serious adverse consequences on digestive diseases research.

In addition the Board has carefully reviewed the recommendations of the Digestive Diseases Commission and the experience of Arthritis and Diabetes with their centers programs. It has concluded that certain research problems and opportunities may best be addressed by a variety of experts in basic and clinical science working together in the context of a center. The Board is dismayed to learn that the proposed administration budget eliminates new centers grants and hence does not provide the opportunity for the initiation of a Digestive Diseases Centers Program.

The Board strongly recommends that funds be allocated to digestive diseases for development and establishment of a Digestive Diseases Centers Program comparable to those successfully created in Arthritis and Diabetes. Specifically, the Board recommends $8 million in FY 84, and $9 million in FY 85, and $10 million in FY 86.

The Board also recommends that a Digestive Diseases Data System be established for the indentification of risk, prognostic, and diagnostic factors relevant to digestive diseases and to augment existing activities of the National Center for Health Care statistics and the Health Care Financing Administration.

The increased use of computers to record medical information offers a unique opportunity to accumulate precise and readily retrievable data on digestive diseases and disorders to obtain and record data in a standardized and accurate manner. It is particularly important to initiate a program now before a multiplicity in uncoordinated systems develop because of the multitude of disorders which comprise digestive diseases. Endoscopic procedures offer a unique opportunity around which to develop data system, because many are so new that systems of recording are still under development. Therefore this opportunity should be pursued immediately.

The continuation of the National Digestive Diseases Clearinghouse is also recommended. Funding for these latter two programs is recommended at $1 million in FY 84, $1.1 million in FY 85, and $1.2 million in FY 86.

The Board supports appropriations of 473 million dollars to the National Institute of Arthritis, Diabetes, and Digestive and Kidney Diseases for FY 84 which will restore the proposed reductions in new and competing grants, restore a Centers program in the Institute, and restore funds for intramural research. The Board recommends that funds be specifically designated to develop a program of Digestive

Disease Centers such as those in Diabetes and Arthritis, and Digestive Diseases Data Systems as those in Diabetes and Arthritis.

The Board recommends that it receive a proper level of funding in order to continue with its efforts to evaluate and to cause to be implemented the National Plan to Combat Digestive Diseases.

We appreciate every effort that you have made to assure that the health of this nation is secured through legislation from your Subcommittee.

Thank you for the privilege to appear before you. I will be happy to respond to questions or comments.

STATEMENT OF CONSTANCE COOPER, BOARD MEMBER, COALITION OF DIGESTIVE DISEASE ORGANIZATIONS

Senator WEICKER. Constance Cooper, board member of the Coalition of Digestive Disease Organizations.

Nurse Cooper. Right?

Ms. COOPER. Yes, Nurse Cooper.

Good morning, Mr. Chairman. I am Connie Cooper. I'm a registered nurse. I have worked with the gastrointestinal and digestive disease patients for more than half of my 20 years in nursing. I am currently a board member of the Coalition of Digestive Disease Organizations, because I am the president elect of the Society of Gastrointestinal Assistants, which are nurses and allied people working with digestive disease patients.

I speak to you today as a board member of the coalition and because of mine and the coalition's interest in the digestive disease patient. Over the 10 or so years that I have worked with the patients there has been a slow, steady advance in the technology and in the diagnosis and treatment of the digestive disease patient. However, prevention for digestive diseases has not come to the forefront. Therefore, we feel strongly that the appropriations to the NIADDK and specifically digestive diseases are inappropriate.

The coalition agrees wholeheartedly with Dr. Sherlock that we feel that an appropriation of $475 million to NIADDK and $80.5 million to digestive diseases would be appropriate to allow an advance in research.

The coalition also would like to see some funding for digestive disease centers. We agree with him on that. We feel as though the level of appropriation for funding for the Education Information Clearinghouse is inappropriate.

One thing that has not changed in a number of years is the fact that it is not proper to talk about bleeding from the bowel, to talk about gas, belching. These things are just kept low keyed. However, symptoms of this sort in excess can show very serious impending digestive disease. People just don't want to talk about those sort of things.

For this reason, and because of the economic loss to the Nation for patients with digestive diseases of $40 billion in lost wages, we feel that the appropriation should continue, and we'd like to see some more work done in research.

Senator WEICKER. Thank you.

Ms. COOPER. Any questions?

PREPARED STATEMENT

Senator WEICKER. No; I have no questions. I thank you very much for your testimony.

Ms. COOPER. Thank you.

[The statement follows:]

STATEMENT OF CONSTANCE COOPER

I am Connie Cooper, R.N., a Gastrointestinal Assistant and a Board Member of the Coalition of Digestive Disease Organizations, which represents 17 lay and professional organizations with primary interest in digestive diseases, health care, research and education.

Today, I represent more than 20 million Americans with all the digestive diseases listed on a chart attached to my statement.

We are very much the silent masses. People do not feel comfortable talking about inflamed bowels and bleeding from the rectum, or constipation and gas, and other such unusual topics of conversation.

Digestive Diseases are not taken seriously or even thought of as life threatening until the severe pain lingers on, and a patient ends up in a hospital, perhaps hooked up to machines from every orifice in the body.

It is not generally known that the category of digestive diseases accounts for an economic loss to the nation of some $40 billion every year in lost wages, disability payments, health care costs and lost tax revenues. Neither is it well known that almost one third of all cancers affect some part of the digestive system. Some 20 million Americans suffer from chronic digestive disorders, and about 14 million cases of acute digestive diseases are treated in this country every year.

National Digestive Disease Information Clearinghouse

Fortunately, Congress, learning from the Digestive Disease Commission about the lack of any nationally organized mechanism that could deal with the multiple and diverse digestive education requirements, established the National Digestive Disease Information Clearinghouse.

The Clearinghouse was mandated to educate the public, patients and physicians about what is needed to be known about the prevention and treatment of dozens of digestive diseases.

The Clearinghouse has some minimal funds allocated to it from the NIADDK budget, but it is provided at the expense of important research projects. Under the current budget constraints and the Administration's policy on dissemination of information, the Digestive Disease Information Clearinghouse is doing the best it can.

Like the organized hypertension community, combined with the Heart, Lung, and Blood Institute, which have made a significant educational impact on the American public regarding the prevention and treatment of heart disease, so too, does the digestive disease lay and medical community understand the extraordinary void that exists concerning digestive health and disease, and we have begun to do something about it. That important partnership is essential if real progress is to be made.

An opportunity such as today, to share with this prestigious Subcommittee the very serious concerns of the digestive disease patients and providers who treat them, is one step in the right direction.

National Digestive Disease Advisory Board

In order to organize and coordinate any short or long term national plan to combat digestive diseases, it was essential that the National Digestive Disease Advisory Board be established and adequately funded so it, like the National Diabetes Advisory Board and the National Arthritis Advisory Board, can provide valuable contributions to the improvement of Federal Digestive Disease Programs and facilitate coordination with other governmental and nongovernmental activities. Congress, in its wisdom, authorized this Board two years ago, and it is now in place and functions well under the leadership of Dr. Paul Sherlock, Chairman, Department of Medicine, Memorial Sloan-Kettering Cancer Center in New York. Our experience in dealing with the Digestive Disease Advisory Board has always been absolutely productive, and is a fine example of how well the government and private sector can work together to accomplish mutual goals and compliment each others efforts. We highly recommend continued support for the DD Advisory Board.

Research Opportunities In Digestive Diseases

I would like to discuss a few of the advances that are leading to research opportunities in the field of digestive diseases.

(1) Over the past 25 years we have developed instruments that contain flexible glass fibers through which one can look directly inside the gastrointestinal tract and see ulcers, lesions, and tumors in the stomach, esophagus, and intestinal tract. The instruments (Endoscopes) have greatly altered the practice of Gastroenterology. The available technology offers possibilities for major advances. We may be able to directly study clinical problems such as Gastrointestinal Circulation and secretion in patients with disease. The Endoscope is truly an exciting tool and new clinical and research applications are being discovered all the time.

(2) Knowledge of the circulation is important to our understanding of, and ultimately the treatment of, several disorders. For instance, stress related erosions of the stomach and upper intestine may bleed and lead to death in patients who are already dangerously ill. In these patients, evidence suggests that the stomach and intestinal wall may be vulnerable to erosion because of impaired circulation.

Such knowledge may also be important to our understanding and development of a treatment for the more common forms of peptic ulcer. These ulcers occur in people who are otherwise well. Knowledge of the vascular changes during the formation and healing of ulcers could lead to a better understanding of the factors that cause ulcers and hopefully lead to improved treatment and perhaps help prevent the recurrence of this common digestive disorder.

(3) As you may know, the digestive tract is very susceptible to the effect of emotions and stress. Recent advances have shown that bio-chemical and hormonal compounds that control digestive tract functions are also found in the brain, suggesting a possible relationship. Further research, such as that which is occurring in the Ulcer Center in California, should help us understand this relationship.

(4) Another series of opportunities for research results from the ability to put a catheter into small biliary ducts and obtain bile samples close to the sites where it is formed in the liver. It is likewise possible to obtain successive samples of bile as it passes down through the larger ducts that finally drain into the Gallbladder, and then into the intestine. Such samples should provide precise information on the bile as it is formed and changes that occur as it passes down the ducts, with the hope that the insights gained from this will provide further useful information on the causes and treatments for gallstones. Using catheters, we can introduce substances into the ducts, which dissolve gallstones, and study how they work, and what their limitations are.

(5) Possibly as important is the opportunity to study the pancreatic secretion in the pancreatic ducts. Pancreatitis is a common disorder that can be fatal, and in many cases becomes disabling because of frequent recurrence which ultimately may destroy the pancreas. Pancreatitis is associated with alcoholism, biliary tract disease, and high fat levels in the blood. We do not know how many of these disorders cause pancreatitis. The pancreas has been very difficult to study. Until recently we could not abstract pure secretions from the pancreas, but could only obtain the pancreatic juice after it had passed into the intestine and had become contaminated with intestinal contents. With the use of the Endoscope, we can now obtain pure secretions near the site where it is secreted, and also observe changes in its composition as it passes down the ducts. We already know

there are some important changes, and stones may even form in the ducts. It may be possible to observe the effects on pancreatic secretions of alcohol, of high blood fat, and of biliary tract disorders, and translate these observations into better understandings which ultimately may lead to treatment and therapy for this disease.

(6) Nutrition is an area of great public interest and importance. NIADDK now supports five clinical nutrition units that represent a new multidisciplinary approach to nutrition research. It is envisioned that by integrating nutrition activities in medical institutions that support research, training, and patient care, knowledge about specific nutrients and their effect on health, human development, and the prevention and treatment of diseases will be generated. Research funds focused here could have significance both for children and for adults whose diseases or nutritional unbalances start in childhood.

(7) Liver transplantation is not a new idea, but for a number of reasons has remained a very uncommon therapy for chronic and acute liver failure. Many of the early surgical problems seem to be resolved and certain new adjuvant drugs, especially Cyclosporin A, have resulted in improved control of post transplantation rejection problems. The most recent survival figures are very encouraging and there are patients living as long as 14 years following a liver transplant. It is estimated that for the 5,000 potential candidates for such therapy, there exists a pool of 12 to 60 thousand donors. Hence, organ availability does not now seem to be a limiting factor. Because of the special needs and surgical skills required, this is one area which could benefit from the establishment of one or more Liver Transplant Centers. At present, a center would be most likely to provide the optimum of clinical care while continuing to provide quality research at a cost effective level.

Digestive Disease Centers - Data System

The Coalition of Digestive Disease Organizations, and the entire Digestive Disease Community, have endorsed and supported legislation pending before the House and Senate Authorizing Committees that would greatly enhance our efforts in establishing Centers of Excellence and a Data System.

This authorization would:

A. Establish Digestive Disease Research Centers. Several of the research advances and opportunities I have discussed may best be addressed and coordinated by a variety of experts in both basic and clinical science working together in the center concept. Centers provide a unique opportunity for interdisciplinary and collaborative research where basic scientists can interact with clinical scientists and clinicians to effectively investigate a major disease problem. This concept is evident in the accomplishments of the two current Liver Centers and Peptic Ulcer Center, and has also been evident in other disease areas.

B. Establish an Epidemiological Data System Program. The present system for data collection on nationwide prevalance, seriousness, and distribution of digestive disease is totally inadequate. With the establishment of a Digestive Disease Data System, long term studies are possible in order to follow developmental aspects of diseases and disorders, and to control and measure the impact where possible of new technologies, of methodologies, and of medical interventions. Clearly, a dedicated data processing system for clinical data on digestive diseases is needed (it does not exist at the present time). This system could be used to collect population based total inpatient and outpatient digestive disease statistics. It could also be used to assist in the assessment of the social and economical impact of chronic digestive disease and could be used to measure the full impact of digestive diseases on Medicare expenditures.

Authority for these Centers of Excellence and Data System is pending before both Houses of Congress. Chairman Waxman of the House Health and Environment Subcommittee has included language in his NIH Reauthorization Bill to establish this authority; and Chairman Hatch of the Senate Labor and Human Resources Committee recently indicated during Committee hearings on the NIH Reauthorization a strong interest to provide for this legislation in his Bill.

Hence, as soon as this authority is provided for, we will look to this Committee for appropriate consideration.

NIADDK

Today, we want to speak up, too, for the National Institute of Arthritis, Diabetes, Digestive and Kidney Disease. The President's budget is woefully inadequate for NIADDK. Both NIH, generally, and NIADDK are experiencing funding squeezes that will have a long term impact on the quality of America's health. The budget figure suggested by the President for NIADDK is a cut in real dollars and is substantially less than what is needed to function at current operations.

Important research opportunities are being ignored, and these trends, plus reduced training money, are convincing many good scientists that it is no longer advisable to plan on a career in biomedical research.

We believe that NIADDK should receive at least $473 million in FY 1984. At a level of $473 million, the Institute could fund about 35 percent of it's approved research applications, and have some money to strengthen other research programs as well, including research training, clinical trials, centers, and data systems. An appropriation of $473 million for NIADDK would still require almost two-thirds of scientifically meritorious grant applications to go unfunded, but it would represent a major step toward promoting greater understanding of this important group of health problems. At least $9 million of this increase should go to support digestive disease programs and opportunities, and no less than $80.5 million of the total NIADDK budget should go to support digestive disease and nutrition concerns.

Mr. Chairman, Digestive Diseases is the runt of the litter in NIADDK. It needs special care to become a viable entity capable of preventing some of the suffering caused by dozens of diseases.

We have coordinated our digestive disease forces to have a unified appeal to Congress through this Coalition.

We are anxious to join with this Committee to take the next vital step to gain additional support for millions of Americans afflicted with digestive diseases.

Thank you for the opportunity to present our concerns.

American Celiac Society
American College of Gastroenterology
American Gastroenterological Association
American Liver Foundation
American Society for Gastrointestinal Endoscopy
American Society for Parenteral and Enteral Nutrition
Center for Ulcer Research and Education Foundation
Children's Liver Foundation
Dean Thiel Foundation
Gluten Intolerance Group
International Association for Enterostomal Therapy
National Foundation for Ileitis and Colitis
North American Society for Pediatric Gastroenterology
Pediatric Liver Research Foundation
Society for Gastrointestinal Assistants
The Society for Surgery of the Alimentary Tract
United Ostomy Association

STATEMENT OF DR. NEENA B. SCHWARTZ, PRESIDENT, ENDOCRINE SOCIETY

Senator WEICKER. Dr. Neena Schwartz, president of the——

Dr. SCHWARTZ. Endocrine Society.

Senator WEICKER [continuing]. Endocrine Society. I've heard of endocrinologists. I just never came up with the word endocrine.

Dr. SCHWARTZ. Well, the Endocrine Society is the major society in this country, in fact in the world, representing about 4,000 scientists and physicians who are interested in hormones and endocrine glands.

I'd like to talk today about the advances that have been made recently in endocrine research, and the necessity for supporting this continuously through NIH awards.

We've been shocked by the budget proposed by the President for 1984, as you've been hearing all morning. We're particularly disheartened by the budget request for new and competing research grants and training grants which would effect a large reduction below the current year.

In the light of the Carnegie report that we heard yesterday, I think this is not a time for the Government to be discouraging biomedical research and talented researchers.

Most endocrine research falls within the NIADDK and NICHD, so I'm going to focus on those two institutes.

The President's January budget provided funding for NIH for only 3,676 competing grants, and the Department is now claiming that this can be increased to 5,000 grants. But we know that in order to fund these additional grants that we will be forced to reduce direct and indirect costs on current research grants, in effect robbing Peter to pay Paul, which is a policy we cannot support.

It is clear to us that if NIH is to fund properly 5,000 competing grants that it will need to increase appropriations over the administration's request. We feel that an appropriation for NIH in fiscal year 1984 of $4.491 billion is not only justified but required. This would permit real funding of 5,000 new competing grants as well as 10,000 research training positions.

I'm a trainer of people in reproductive endrocrinology. I've had a training grant from NIH for 5 years, and it has been increasingly difficult for us to get people applying to these training programs for the reasons that we've been hearing about all morning, that students, both physicians as well as Ph. D.'s, are discouraged right now.

They see me going through my roller coaster every 3 years for my own grants and they don't necessarily want to do the same thing.

Let me focus on just a couple of major accomplishments that we feel endocrinology has presented this country in the last few years.

A major breakthrough in endocrinology has been using recombinant DNA techniques to manufacture human insulin and growth hormone. As you know, these protein hormones are species-specific. We cannot give humans protein hormones from other species. And the DNA techniques have permitted these now to be in essentially unlimited numbers.

This year scientists supported by NIH have identified a growth hormone releasing factor from the brain. This factor is already in fact being used in the treatment of dwarfism and will probably find an application in treatment for wound healing and burn therapy.

Another recent finding in endocrinology has been a demonstration that infertility which is genetic in animals can be controlled by a specific area of the brain, and that brain transplants can overcome this infertility. Now human applications of this information are obviously still in the future, but it represents an important gain in our knowledge of the brain.

Despite the fact that endocrinology is one of the most rapidly developing areas of biomedical science, and despite the fact that endocrine systems really pervade nearly every function and many diseases of the body, support for this research has declined relative to other research areas over the last decade.

So we would suggest that not only in addition to providing funds at the levels we are suggesting, we hope that the subcommittee will take note of the disparity that exists with respect to the allocation of funds for endocrine research within the NIADDK.

Thank you very much for your attention.

PREPARED STATEMENT

Senator WEICKER. Thank you very much.

[The statement follows:]

STATEMENT OF DR. NEENA B. SCHWARTZ

My name is Dr. Neena Schwartz. I am President of the Endocrine Society, which represents over 4000 scientists and physicians devoted to the study of endocrinology.

I am here today to discuss the advances being made in endocrine research and the necessity for appropriating sufficient funds for this and other programs conducted by the National Institutes of Health to allow such research to go forward at a level commensurate with its importance and value to society.

There is no question of the substantial contribution biomedical research has made in this country, both to the health of our citizenry as well as to our economy. It is estimated that each research dollar produces $13 in savings from prevention of illness, avoidance of medical costs, and increased life expectancy. Much of the progress that has been made can be attributed to research carried out at universities under grants from the federal government.

A budget for NIH such as the one proposed by the President for FY 1984 is shocking in its lack of support for medical research. Specifically, we are disheartened by the budget request for new and competing research grants and research training grants, which would effect a large reduction for FY 1984 below the current year. At a time when the government should be encouraging biomedical research and talented researchers, it is signaling just the opposite.

Because much of the endocrine research that is our primary interest falls within the program authority of the National Institute of Arthritis, Diabetes and Digestive and Kidney Diseases (NIADDK) and the National Institute for Child Health & Human Development (NICHD), I will focus my remarks on these two institutes.

In January of this year, the President submitted a budget to Congress of $4.077 billion for NIH, which included a budget of $419.6 million for NIADDK and $257.3 million for NICHD. In submitting this budget, then-Secretary Schweiker urged that the figures in the budget be changed to achieve the goal of funding 5,000 new and competing research grants. In March, Secretary Heckler submitted a revised budget to Congress which purports to meet this goal, but in fact falls far short. The new figures, while maintaining a request of $4.077 billion for NIH as a whole, include a budget of $426.4 million for NIADDK -- an increase of $6.7 million over the January budget request -- and $256.6 million for NICHD -- a decrease of $756,000.

The reasons for this drastic budget revision are obvious. The President's January budget provided funding for only 3,676 competing grants. Although the Department now claims that it has increased that number to 5,000, the increase was accomplished by trickery -- not with dollars. In order to fund the additional grants, NIH will reduce its payments for both the direct and indirect costs of every research project grant -- in effect, "robbing Peter to pay Paul," a policy we cannot support. Critical programs have been reduced in order to fund the 5,000 grants without increasing funding, including $51.2 million from research centers; $24.8 million from noncompeting and supplemental research project grants; $25 million from biomedical research support grants; $5 million from research training; $20 million from R&D contracts; and $4.9 million from intramural research. Research training positions that we must have to develop the next generation of scientists would decline from 9,968 to 9,100.

The centers programs at both NIADDK and NICHD which are principal targets of the revised budget have been particularly useful. The NIADDK centers for endocrine research and endocrine-related research in diabetes have helped to bring research advances to patient care. At NICHD, population research centers (where endocrinologists play important roles) are studying problems of fertility and infertility. Their studies of biochemical functions associated with reproduction hold the hope of better, safer contraceptive methods for controlling fertility. At the same time, this research provides the information necessary to aid couples desiring to have children in overcoming problems of infertility. Also of great value are the General Clinical Research Centers supported by the Division of Research Resources.

But all of these programs are directly threatened by the Administration's plan to deny refunding to centers that have grants which happen to expire next year. Irrespective of scientific merit, the Administration plans to terminate support for many centers because of the vagaries of the funding cycle. We urge that this Subcommittee not allow such an arbitrary and capricious result to come about.

It is clear that, if NIH is to fund properly 5,000 competing grants, it will need increased appropriations over the Administration's request. We feel strongly that, in order simply to maintain essentially the same level of activity in FY 1984 as in FY 1983, an appropriation for NIH as a whole of $4.491 billion is not only justified, it is required. This will permit full -- not sham -- funding of both the direct and indirect costs of 5,000 new and competing grants. Cuts in existing grants would be restored. Research training slots would approach 10,000. And the severe and arbitrary reductions planned for center programs would be avoided. Such funding for NIH would permit appropriations for NIADDK of $475 million and

NICHD of $281.6 million, the minimum levels we believe are needed for these institutes to continue this valuable work.

I would like to focus on several major accomplishments that have been made in endocrinology in recent times in order to demonstrate the need for the budget we are requesting.

Major breakthroughs have been made in the synthesis of insulin and growth hormones using recombinant DNA techniques. These advances give us the potential of an unlimited supply of insulin, human growth hormones and other peptide hormones -- all of which must now be painstakingly produced in small quantities from natural sources.

In another significant advance, scientists have recently identified a growth hormone releasing factor (GRH) from the brain. GRH will be used in the treatment of dwarfism, which is caused by the pituitary gland's secreting an insufficient amount of this growth hormone. In addition, GRH will very likely find an application in treatment for wound healing and burn therapy, and possibly in other debilitating diseases.

As a further example of the important work being done in this field, there are indications that genetic infertility can be reversed surgically. Recent research in animals has demonstrated that genetic infertility is controlled by a specific portion of the brain. Transplants in genetically infertile animals have proven effective in reversing this condition. While human applications of this information are still in the future, it represents an important gain in our knowledge of the brain and its processes.

These are but a few examples of vitally important knowledge being developed through endorsed research. Despite the fact that endocrinology is one of the most rapidly developing areas of biomedical science, however, and despite the fact that the endocrine system in its pervasiveness affects virtually every function and many of the diseases of the body, support for this research has declined relative to other research areas over the last decade. In 1972, endocrinology received 32.6% of the funds allocated to the diabetes, endocrinology and metabolism (DEM) research cluster of what is now NIADDK. By 1981, this share had declined to 22.6%. Put somewhat differently, funding for the DEM cluster grew by 172% during this period, but the amount allocated for endocrine research grew by only 89%.

For this reason, in addition to providing funds at the levels we have suggested today and believe are fully justified, we hope that the Subcommittee will take note of the disparity that exists with respect to the allocation of funds for endocrine research within NIADDK. We urge that you recommend in your Committee report that steps be taken by the Institute staff to remedy this situation.

Thank you for your kind attention.

STATEMENT OF DR. JOHN P. PAPP, CHAIRMAN, LEGISLATIVE COMMITTEE OF THE AMERICAN COLLEGE OF GASTROENTEROLOGY

Senator WEICKER. Next we have Dr. John Papp, chairman of the legislative committee of the American College of Gastroenterology.

Dr. PAPP. Good morning, Mr. Chairman.

Thank you for the opportunity to present the views of the American College of Gastroenterology. I speak today representing the practical gastroenterologists who apply the practical aspects of NIH research to patients who need medical care.

As a gastroenterologist, I can tell you that the past few years have been exciting. Never before have we seen such magnificent opportunities in research that puts new light on the causes, treatments, and cures of disorders of the digestive tract. We have had a chance through research to enable practicing physicians to treat patients much more effectively and at reduced costs.

Through the use of an endoscope, which is a flexible, fiber optic, tubular instrument we can now examine the digestive tract. We can examine patients with actively bleeding ulcers, and diagnose the site of bleeding. We can cauterize the area and stop the bleeding, and thus avoid some major surgery in patients.

Not only does it avoid surgery but it reduces the costs of hospitalization and provides for less time spent in the hospital and allows for more early return of patients to work.

Since a large majority of our patients with gastrointestinal disease are elderly, with complex medical illnesses, they are poor candidates for surgery. By using the endoscopic electrocoagulation technique, we reduce the mortality and morbidity from bleeding.

This example I use is by no means the only advance made in research of the treatment of gastrointestinal disease. There are many, many more. But this single advance in patient care was facilitated by 10 years of research. As patients are well aware, many of the treatments and procedures that we perform daily have been analyzed, criticized, evaluated, and finally clinically performed. Without the necessary careful research of disease, we in medicine would still be back in the Dark Ages.

The American College of Gastroenterology respectfully recommends an appropriation for this important research at the National Institute of Arthritis, Diabetes, Digestive, and Kidney Diseases of about $473 million, of which no less than $80.5 million will be provided for digestive diseases.

We, as others before, have supported the Centers of Excellence for Digestive Disease Research, and the appropriate support for establishment of funding of an epidemiological data system.

We also ask that you consider supporting an extension of the Digestive Diseases Advisory Board which has always been responsive and helpful to us.

Thank you for the opportunity to express our concerns.

PREPARED STATEMENT

Senator WEICKER. Dr. Papp, thank you very much for your testimony. I appreciate it.

Dr. PAPP. Thank you.

[The statement follows:]

STATEMENT OF DR. JOHN P. PAPP

Thank you for the opportunity to present views of the American College of Gastroenterology. I speak today representing the practicing physicians who apply the research that is funded through NIH, to patients who need medical care.

NIADDK

As a Gastroenterologist, I can tell you that the past few years have been extremely exciting. Never before have we seen such magnificent opportunities in research that puts new light on the cause, treatment and cures of disorders of the digestive tract. We have a chance through research to enable practicing physicians to treat patients much more effectively at reduced costs.

For example, through the use of an Endoscope, a special flexible, tubular instrument with optic fibers, we can now see into the Gastrointestinal Tract and make judgments that, until recently, would have necessitated abdominal surgery. We can now, through the use of an Endoscope, locate the site of bleeding in the Gastrointestinal Tract and cauterize the area to stop the bleeding. This is not only a more sound medical procedure, but a less costly one to the patient, and provides for less time spent in the hospital recovering. Since a large majority of patients with gastrointestinal diseases are elderly, making them poor candidates for surgery, this type of procedure enables us to help a greater number of patients who experience diseases of the digestive system.

This example I use is by no means the only advance made in research of the treatment of Gastrointestinal Disease. There are many, many more. But this single advance in patient care was facilitated by research. As physicians are well aware, each and every one of the hundreds of medical procedures we perform daily have been studied, analyzed, scrutinized, cross referenced, tried, constructively criticized, evaluated, and finally, clinically performed. So without the careful research of the causes, treatment, and cures of disease, medicine would still be back in the dark ages. The American College of Gastroenterology respectfully recommends an appropriation, for this important research at the National Institute of Arthritis, Diabetes, Digestive and Kidney Disease (NIADDK), of $473 million, of which no less than $80.5 million be provided for Digestive Disease research and support.

Centers, Data System, and Advisory Board

The American College of Gastroenterology would like to express its support, pursuant to enactment of pending legislation, for the funding of Centers of Excellence for Digestive Disease Research, and appropriate support for establishment and funding of an Epidemiological Data System to provide a wider base of information for researchers. ACG also supports the extension of the Digestive Disease Advisory Board, which has always been responsive and helpful.

Medicare and Medicaid

The poor and elderly who depend extensively on the nation's two largest medical health plans, Medicare and Medicaid, cannot withstand any more benefit reductions or cost shifting schemes. It is a tragedy that these systems have been severely impaired under the guise of competition, reform, restructuring, cost awareness, cost consciousness, efficiency improvement and the like. This rationing of health care boils down to an increased financial burden and benefit reductions to those who can least afford it. The nation's poor and elderly have some right to adequate medical care. If nothing else, each person in our country should be able to seek professional medical care without the fear of depleting all of their financial resources or being unduly processed through a medical system that does not want to adequately treat a patient because they are not being wholly compensated for their efforts.

Recently, Congress passed legislation that will pay hospitals on a prospective basis. While we certainly hope this proves to be an equitable means of containing costs while maintaining adequate care, ACG intends to monitor the effect this program change has on it's recipients, the patients.

Training of Professionals

The American College of Gastroenterology fully recognizes the need for federally funded health professions programs to gear their training efforts toward the needs of the population of the nation. The percentage of aged individuals in this country is increasing every year, and we must prepare the medical profession for the extraordinary increase in incidence of illnesses associated with the aged. In the next few decades Gastroenterologists expect to experience an uptrend in patients with digestive tract disorders. Now is the time to prepare.

Thank you for the opportunity to present our concerns.

PREPARED STATEMENTS

Senator WEICKER. The committee will now be chaired by Senator Mark Andrews.

Thank you very much, Mark.

Senator ANDREWS [presiding]. Before we begin with Dr. Overholt, I have a brief statement that I would like to put in the record at this point in time, preceding a statement for the record by Dr. Donald Kennedy, president of Stanford University. And we'll put that in the record here at this particular point in time or wherever, during today's hearing, it seems appropriate.

[The statements follow:]

STATEMENT OF SENATOR MARK ANDREWS

As we examine the proposed budget for the National Institutes of Health, I am especially interested to ensure that our investment in biomedical research is sufficient enough sustain the extraordinary work done under the auspices of the NIH at the research universities of this country. American biomedical research is justly admired throughout the world, and the basis for America's remarkable success in this field has been the wise stewardship of the National Institutes of Health in its peer review system to select the best research and its adequate funding of that research, including its direct and indirect costs.

Quality research is costly, but in the long run adequate funding of research is far less costly to society than trying to buy research on the cheap. Failing adequately to pay for direct costs or cutting reimbursement for legitimately incurred indirect costs will surely result in the erosion of the scientific and institutional base essential for the conduct of research. I am deeply concerned that we not underfund research by permitting budget pressures to take priority over sound funding principles. The admirable goal of funding 5,000 grants per year was set some years ago, and it is still an admirable goal. But that goal is for 5,000 adequately funded grants. We must not permit the pursuit of a set number of grants, which might be scrawny in direct and indirect funding, to become the objective itself. We must pay careful attention to a healthy long-term research policy, and that means having no truck with disguised underfunding of research.

There are several reasons to to be concerned about the latest proposal to "save" money by denying reimbursement for indirect costs according to OMB Circular A-21. Among those reasons are the following:

o Cuts in indirect cost reimbursement weaken the research intensive institutions by denying reimbursement for already expended funds; the policy also discourages other institutions from seeking research funds by introducing new uncertainties into the university/government reltionship.

o The policy in the Administration's budget is in direct violation with the spirit of the cost principles that guide the agreement between universities and the Federal government - the universities must comply with these cost accounting principles; the PHS is the only Agency proposing to abandon A-21.

o The "fixed allowance" proposal is no more logical or equitable than last year's proposal to cut 10%.

o The concept of a stable number of grants -5000- was predicated upon this number as a minimum number of fully funded research grants; the concept has been misconstrued to represent an abstract number having more relevance than the actual funding of research.

o The proposed cuts in reimbursement of indirect costs would specifically weaken that part of the research enterprise -- facilities and equipment -- that both the Congress and the Administration have recognized as being in dire need of revitiiization.

STATEMENT OF DONALD KENNEDY, PRESIDENT, STANFORD UNIVERSITY

For two years now, the National Institutes of Health has been trying, by administrative means, to compel a reduction in the reimbursement of indirect costs NIH owes universities under established government rules. Last year, an arbitrary 10% reduction in recovery was proposed; it was averted when the Congress recognized the effort for what it was and instructed the agency not to do it. This year the attempt has been renewed in a more complex disguise: NIH proposes to reduce indirect cost recovery by a formula that would decrease reimbursement in proportion to the ten-year history of indirect cost recovery in each grantee institution.

Now, this is not the first time that the universities and the government have addressed the problem of indirect cost. It has been repeatedly recognized that the indirect costs of doing research are real costs, even though they cannot be specifically identified with individual projects. The universities are spending real dollars to pay them, and therefore--if they are not reimbursed--university general funds must support them. The cost-accounting principles used to calculate these costs, and thus to set the recovery rate, have been worked out over the course of years of negotiation between the universities and the government. The Office of Management and Budget is not exactly noted for its soft, cozy approach to how the government's money should be spent, and the cost-accounting principles are OMB's.

But because the costs are indirect, they naturally arouse some suspicion in members of Congress and others who encounter them for the first time. That is why numerous studies of their appropriateness have been ordered and performed by the General Accounting Office and by independent auditing firms. In each case, these studies have documented both the reality of the costs and the appropriateness of the accounting principles under which they are reimbursed. And the reimbursements are made only after government-conducted audits of actual expenditures at the recipient universities.

So why, after all this history, are there now questions about indirect costs? The answer is that one government agency among many--NIH--has set itself some goals for research support that are impossible for it to accomplish within the resource limitations established by the President's budget. It has decided unilaterally that the number of grants is somehow more important than adequately funding research according to the recommendations of study sections and in accordance with accepted cost principles. This will result in the awarding of greater numbers of grants, at the expense of university general funds and the quality of research. It is, in other words, a new and creative form of forced cost-sharing. For a university like mine, the largest single source of unrestricted revenue is tuition; therefore the effect of a failure to reimburse the real costs of research is to move student tuition dollars to the support of faculty research. NIH has made its proposal superficially attractive to a few principal investigators, who see it as a way to increase their own research support. Others, who understand that it will merely require the reallocation of tuition income from such other expenses as faculty salaries and building maintenance, are less enchanted with it.

What bothers the universities most about this proposal is the understandings it abrogates. Years of faithful institutional effort went into the negotiations of the cost principles in OMB Circular A-21, and--before that--into building an understanding with Congress and the Executive Branch about the legitimacy of indirect costs. A-21 represents a compact with our government. We are not free to change the accounting principles, or to alter OMB's disallowances of what we regard as legitimate costs. But, it now turns out, a single government agency can apparently jettison the agreement when it pleases. Appeals to OMB, to the Office of Science and Technology Policy, and to the Secretary of Health and Human Services have elicited sympathetic hearings and helpful comments, but no insistence that NIH alter its budget proposal. We have, in effect, been told that it is up to Congress to insist that the Executive Branch play by its own rules.

What justification does NIH present for this extraordinary action, apart from its desire to fund a larger number of grants? It asserts that indirect costs have risen at an unacceptably high rate: they have used phrases like "out of control" and "disproportionate growth," enhancing the impression that something untidy and quite possibly illegal is going on. In fact, there are a number of perfectly good explanations for the increases that have occurred in indirect cost rates. First, costs in universities that are more intensively associated with research than with other activities have been growing faster than the rate of inflation. This alone will increase the indirect cost rate. Second, in funding the *direct*-cost component of research proposals NIH has consistently understated the actual rate of cost rise. That will make indirect costs rise faster than directs. Third, equipment sharing and increasingly complex research requirements have resulted in more pooled costs that are legitimately attributable to the indirect cost categories. Finally, better management and improved identification of costs--required by government rules--has often resulted in the identification of more costs that must be allocated to research. In fact, the indirect cost rates charged by universities are far below those charged by private industry or by non-profit, non-academic research organizations. It is simply not legitimate to argue that increases in the indirect cost rate over a period of years amount to a wrong that must be put right.

Now let me turn from the *general* issue of indirect costs to the *specifics* of the proposal NIH has made. The NIH formula would base each institution's indirect cost reimbursement on a level equal to its average percentage of total costs over the last decade. In other words, institutions that have experienced significant rises in indirect costs over the preceding ten years will be affected heavily, whereas those that have experienced little increase will be held harmless. There are a great many things wrong with this proposal, but three are especially disturbing, and I want to discuss them in turn.

(1.) THE PROPOSED FORMULA WOULD IMPACT DIFFERENT KINDS OF INSTITUTIONS DIFFERENTIALLY, AND UNFAIRLY

In essence, the formula selected by NIH will be hardest on institutions that have kept careful track of indirect costs and done the cost-accounting studies necessary to identify and allocate them. Some State institutions, for example, have lower indirect cost rates because reimbursements from the Federal Government are not returned directly to the university; instead they go directly to the State treasury. Those universities therefore have had little incentive to fund the cost-accounting activities necessary to justify realistic overhead rates and as a result their rates have been low, and relatively constant. It would be a bizarre public policy indeed to reward such historical accidents at the expense of other institutions, but that is exactly what the NIH proposal will accomplish. At the same time, the proposal is likely to penalize selectively those places that have achieved the highest quality. Partly as a result of NIH support, the most powerful programs of biomedical research have grown up in the nation's major academic health centers. These are the institutions that would pay the largest share of the reimbursement--shortfall--although all universities will feel substantial negative impact.

(2.) THE FORMULA WILL BE CUMBERSOME AND DIFFICULT TO ADMINISTER

Though it purports to be simple, the new and unprecendented formula proposed by NIH is in fact very complicated, and will prove highly problematical to administer in actual practice. Total cost is not a generally recognized base to which we could apply the rate, and such a base would create substantial inequities among the individual projects. Nothing is said about the differential indirect cost recovery rates between off-campus and on-campus projects, or what they would be under the new formula. No plan has been produced that would allow for exclusions from the base, for such items as equipment or subcontracts. No recognition is given to over or under recoveries from prior periods. And what would be done about institutions that have actually showed declining rates since the recent revisions in OMB Circular A-21? Would these be reimbursed at a figure above their current negotiated rates? The frantic haste with which this proposal has apparently been gotten together allowed its authors no time to think through how it might be applied in the real world.

(3.) THE FORMULA WAS ARRIVED AT UNILATERALLY, WITHOUT ADEQUATE CONSULTATION

In its instructions to NIH a year ago, the Congress said (in the report of the House Committee on Appropriations)

> "The Committee is persuaded that indirect costs are a legitimate component of the costs incurred in performing biomedical research and should be adequately reimbursed."

The Committee went on to identify the perception that federally sponsored research may be bearing more than its fair share of these costs, and accordingly it instructed the Secretary of Health and Human Services

> ". . . In cooperation with the NIH director, to make a careful review of this matter, including consultation with the universities and other research organizations most directly affected, and to submit a report setting forth conclusions and appropriate recommendations to the Committee for discussion in advance of hearings on the 1984 budget request."

Shortly after that language appeared, the presidents of the university associations wrote to the Secretary of Health and Human Services, urging that the Department work with us to carry out the directive of the Congress, and proposing an organization from the universities' side. Nearly two months later, we received a letter from the Assistant Secretary for Health stating NIH's intention to consult; but the next real contact did not occur for another three months, on February 14. Then several of us were given three days notice to attend a meeting in Washington--at which, the agency announced, it intended to lay before us five different "policy options" for reducing indirect cost recovery! In effect, we were asked which of several surgical approaches to amputation we preferred.

My colleagues attended the meeting, but only after notifying the Assistant Secretary for Health and the Director of NIH that they were participating under protest. Those representing the universities who were able to get there on short notice tried to get NIH to change its position, but to no avail. It is thus misleading--indeed, disingenuous--to claim that the formula NIH is now offering results from any consultation with the universities. To the contrary, consultation was avoided for as long as possible, and the meeting of February 17 was hastily arranged just before NIH's reauthorization hearing was scheduled to take place. One can only surmise that NIH was embarrassed by its failure to comply with the instructions of Congress; it certainly had something to be embarrassed about.

Let me conclude with one more general observation. If I sound vexed in these remarks, it is because I am. The vexation emerges out of my long respect for the National Institutes of Health, and its relationship to the conduct of biomedical research in this country. I have viewed that relationship from a number of perspectives: as a biology graduate student; as an NIH grantee for twenty-five years; as a professor and then chairman of a distinguished biology department; as a senior consultant to the Office of Science and Technology Policy in the White House, and then as head of a sister agency in the Public Health Service; and finally as the provost and president of a major research university. From every one of these viewpoints, the NIH appears as an institution of extraordinary worth. It pioneered in the development of the peer review system of scientific evaluation, brought the status of biomedical research in the nation's universities to its present extraordinary level, and developed an intramural program in which generations of distinguished investigators received their first exposure to science. We of the academic community have reposed our trust and hope in it through parts of five decades now.

Were this merely an argument about how many grants NIH should fund, or how it should balance its intramural needs against its extramural ones, it could be put down as another friendly family dispute. But it is not about that; instead, it entails a unilateral abrogation of enduring understandings among three parties: NIH, the universities, and the investigators. It will not escape your notice that this issue is almost ideally structured to stir up differences between university administrators and their own faculty colleagues, as well as between the government and some of its most valuable client institutions.

The universities are perfectly prepared to reassess any aspect of the indirect cost recovery provisions on a government-wide basis, in the same way we have in the past. But I do not think we should be asked to suffer huge and unexpected losses as a consequence of a unilateral agency action which is arbitrary, unfair, and undertaken without consultation. It was the Congress who ordered the consultation, and it is the Congress that now must put things right.

Senator ANDREWS. You're lenient over here. In my subcommittee I've been running on a 3-minute timer. [Laughter.]

And then I explain Mark Twain's story, as you recall, about the preacher who came in and was talking about the needs of the poor. He had a great congregation. He was waxing eloquent, and Mark Twain said, "You know," he said, "I looked in my wallet and I had $400 and the message was so compelling that I thought I'd borrow $300 from my neighbor."

And he said, "And then the preacher talked on and on, and my enthusiasm was diminishing by about $100 every 5 minutes. It got hotter and hotter in there and when they finally passed the plate, I took 10 cents out of it." [Laughter.]

So from the words of Mark Twain, let that be a lesson.

STATEMENT OF DR. B. F. OVERHOLT, PRESIDENT ELECT, AMERICAN SOCIETY OF GASTROINTESTINAL ENDOSCOPY

Senator ANDREWS. Our next witness is Dr. Overholt, the president elect of the American Society for Gastrointestinal Endoscopy.

Dr. Overholt, we're glad to have you here.

Dr. OVERHOLT. Thank you, Senator.

I'm a gastroenterologist in the private practice of medicine. I am president elect of the ASGE, a professional society of over 3,000 members. Our testimony is submitted for the record.

Let me introduce some facts to you.

I'm sure you're familiar with the fact that 20 million people have chronic digestive diseases. There are over 200,000 deaths each year from the disease. Fifteen percent of all hospitalizations are due to digestive diseases. Ten percent of the total cost of illness is due to digestive diseases. We have a $35 billion total economic cost, including lost time from work, yet we invest less than $100 million in digestive disease research.

Senator, we would like to express our appreciation to you for sponsoring the Digestive Disease Week resolution.

Senator ANDREWS. If you hadn't mentioned it I would have. [Laughter.]

I'm the primary sponsor.

Dr. OVERHOLT. We appreciate that.

Today I would like to speak in support of endoscopy and digestive disease research.

Dramatic changes have taken place in research in DD due to the endoscope. We can essentially reach anywhere in the digestive tract now with these instruments. Figuratively speaking, the human is the test tube and the key to access to that test tube is the endoscope. Let me elaborate by three specific examples.

There are 200,000 cases of upper GI hemorrhage per year. It's a frightening experience when a patient vomits blood, frightening to the patient and to the family. Ten percent of those people die. Older people who vomit blood like that have a greater risk. Esophageal varices that occur in cirrhosis are one cause.

Through the endoscope we've developed techniques to inject through a needle into the vein a clotting substance that stops the bleeding. The impact of that on just the cost of transfusions and the length of stay in the hospital is enormous.

Bleeding ulcers is a second example. As Dr. Papp mentioned, we can pass through the instrument electrical probes, heater probes, and lasers to stop the bleeding. And preliminary studies show a reduction in morbidity, mortality, length of stay, and cost for the patient.

A third example is the research that's going on within the Institute at this time. Probes are being developed that can be passed through those scopes to measure physiologic and biochemical changes that are occurring in the patient at that particular time.

A self-propelling catheter that can be passed through the instrument and work its way up into the remote recesses of the pancreatic and bile ducts is being developed.

The implications of endoscopy in this area of research is tremendous in terms of understanding or improving our understanding of the pathophysiology of disease and the treatment. I think the enthusiasm was picked up at a recent NIADDK meeting in that particular area.

Senator, our recommendations are listed for the record, but just let me summarize.

We hope that we will have your support and direction for improving digestive disease research and particularly endoscopy and its application, the support of the advisory board, the centers, and the data system, support of $475 million for the NIADDKD funding, and support of NIH for the $5,000 to $10,000 concept without removing the money from the other pocket to support this.

We have testified before your committee before. We understand your clear direction. We hope we will have your continued support.

In closing may I give you a list of supporting organizations for the record that urge funding of the NIADDKD at $475 million.

Thank you.

PREPARED STATEMENT

Senator ANDREWS. Thank you very much, Doctor. You made an excellent statement. You remind us once again that this is not a spending program but rather. an investment program that pays off in great dividends down the line.

Dr. OVERHOLT. Thank you.

[The statement follows:]

STATEMENT OF DR. B. F. OVERHOLT

I am Bergein F. Overholt, M.D., a gastroenterologist in the private practice of medicine and the President-Elect of the American Society for Gastrointestinal Endoscopy. Today I represent the ASGE, a professional organization of some 3,000 physician and surgeon members, who have undertaken specialized training in the use of flexible fiberoptic endoscopes for specialized use in the diagnosis and treatment of patients with digestive diseases. I present our testimony on behalf of the ASGE and our members who are primarily concerned with the delivery of quality care to our patients.

I have testified before your committee on several occasions and would like to emphasize that we are greatly appreciative of the strong and clear support you and your colleagues on this committee have given to research, diagnosis and treatment in digestive diseases.

Our requests to the committee are:

1. Provide direction in bill report language for increased emphasis of endoscopy in digestive diseases research.

2. Provide funding for the continuation of the Digestive Diseases Advisory Board.

3. Provide support for initiating digestive disease centers.

4. Provide funding for a digestive disease epidemiological data system and the Education and Information Clearinghouse.

5. Appropriate a minimum of $475 million to NIADDK to provide for research stability and training within the Institute, as well as sufficient funds for NIH overall to continue the excellent national research program.

6. Provide resources to continue optimum numbers of training physicians within NIADDK and NIH.

Mr. Chairman, in spite of your committee's clear support of NIADDK and NIH, the level of funding appropriated to the NIH over the past decade has essentially been a level line in constant dollars, because inflation and increased direct and indirect costs have essentially neutralized any increased funding to the Institutes. NIADDK has been particularly hard hit. In an attempt to provide maximum support to investigators and trainees, NIADDK this last year has cut significant amounts from its funding of centers (7% in 1982, 8.5% in 1983), contracts (12% in 1982, 30% in 1983), administration (5% in 1982, ceiling in 1983), intramural research (2% in 1982, ceiling in 1983), and individual research project grants (3.5% in 1982, 6% in 1983).

Mr. Chairman, the Administration's budget request of less than a 2% increase for NIH and NIADDK would severely damage any stability left within NIH. The proposed increase would fund only 3,676 grants and 9,100 trainees, far below the desired 5,000 grants and 10,000 trainees, or would devastate the centers programs in the various institutes. ASGE feels the Administration's budget proposal would jeopardize the very future of biomedical research and especially that of digestive diseases research. The long-range implications are devastating.

We, as practitioners, are keenly aware of existing socioeconomic problems among our people, for we see the affects daily. However, as the economy improves, we would hope that additional funding for NIH would take place to provide an adequate support level for research, and to allow replacement of outdated equipment and to upgrade extramural laboratory facilities. For the present, however, we are respectfully requesting a minimum funding level of $475 million for NIADDK which will allow support of approximately 720 new and competing renewal research grants and 915 full-time equivalent training positions, and to fund new digestive disease centers.

Mr. Chairman, I would now like to review with you the dramatic advances that have occurred recently in gastrointestinal endoscopy and that have direct application to patients -- advancements that are exciting, that will improve our understanding of pathophysiology of digestive diseases, and that will improve patient care. ASGE feels these remarkable accomplishments deserve greater emphasis within NIADDK. Such increased emphasis will unquestionably result in additional improvements in patient care and research. We in the ASGE are focusing our attention on the opportunities for endoscopic research in clinical applications, studies of the function of the digestive tract and pathophysiology of digestive diseases. Major advances, if not a revolution, are now taking place in gastroenterological research with endoscopes.

One important contribution of endoscopy is in the treatment of upper gastrointestinal hemorrhage. Looking into the upper digestive disease tract with an endoscope makes it possible to find the source of bleeding in most patients. NIADDK has recognized the role of endoscopy in upper GI hemorrhage. Approximately 200,000 patients are admitted to hospitals annually with this potentially fatal problem. The mortality of patients with significant GI hemorrhage remains at approximately 10%, with older patients being at even greater risk. Recent improvements in endoscopic therapy, including lasers, electrocoagulation, and heater probes, have in preliminary studies, shown a reduction in length of stay, transfusion requirements, costs and mortality. Another advance supported in part through NIADDK is control of acute bleeding from esophageal varices and cirrhosis. This technique, sclerotherapy, essentially involves injecting a clotting/thrombosing agent into the bleeding varix through an endoscope. A clot is created in the vein which prevents further bleeding. Sclerotherapy holds great promise as a means to prevent death from hemorrhage from esophageal varices of cirrhosis. NIADDK emphasis and research in this area would certainly accelerate development of effective therapy.

NIADDK is developing miniature probes (Goldstein S.R. et al, Journal Biochemical Engineering 102, pages 141-146, 1980) that can be passed through endoscopes to measure the pH (acidity-alkalinity) of intestinal secretions. Modifications of these probes will allow, in the patient, direct measurement of blood flow, biochemical reactions, secretions and motility. A thin-walled, self-propelling toposcopic catheter is being developed at the NIH, with support by the NIADDK, which can be passed through an endoscope and can then find its way through small winding ducts. Thus, access to remote portions of the pancreatic and bile ducts, and even to the gallbladder is possible. Once such a catheter has been introduced some sampling of contents may be possible. This catheter and the probes mentioned above will allow the observation of responses to a variety of drugs, physiologic functions and disease states. The catheter potentially would allow, for example, direct infusion of stone-dissolving solutions into the gallbladder. Clearly, remarkable advances in digestive disease research are on the horizon. NIADDK is providing leadership in these areas, and funding should be provided to permit further leadership.

The pancreas and bile ducts are now readily accessible for investigation, diagnosis and treatment through endoscopes. Small probes can be inserted through an endoscope into these organs and samples of pure pancreatic and bile fluids can be obtained for the study of normal and disease states such as chronic pancreatitis and gallstones. This is an important advance, as previously we were unable to obtain samples of "pure" secretions. Through these probes we can also inject x-ray dye. Special cutting wires can incise and open the bile duct to allow removal of common duct stones. Tubes (splints) can be left in place permanently to drain the ducts so as to dramatically reduce the complications of an obstructed bile duct. Miniature tubes can be placed in the bile duct and let out through the nose to allow continuous irrigation with stone-dissolving solutions. Implications for research, for understanding of pathophysiology and for treatment of diseases of the pancreas are profound.

The small intestine can also be studied with endoscopy. It is possible to see the mucosa of the intestine directly. Magnifying devices allow direct visualization of normal and abnormal intestinal mucosa. Little use has been made of these devices until just recently. It is possible now to apply stains to the mucosal wall which may enable us to study the normal and abnormal intestinal mucosa. Additionally, biopsy specimens can be obtained for pathologic and research studies.

The entire colon is readily studied with endoscopes. Improvements in the diagnosis and treatment of diverticulosis, polyps and cancer of the colon are already occurring. The endoscopic removal of colon polyps, which are thought to be a precursor of colon cancer, is a dramatic advance in patient care and has resulted in marked reduction in hospital stays, costs, morbidity and mortality for these patients. A former U.S. Senator underwent this treatment and returned to his pressing work the next day, whereas peviously, major surgery would have been required for treatment. Research is needed in the study of motility disorders, such as irritable bowel and in blood flow changes in the colon. Doppler principles can be applied to determine blood flow. Endoscopic passage of probes for these purposes under direct visual control offers significant advantages. An improved understanding of colonic diseases is possible and NIADDK can and should lead in this area.

Mr. Chairman, we have traveled with an endoscope from one end of the GI tract to the other. Endoscopy now provides accessibility to virtually all areas of the GI tract. The implications for research in digestive diseases are now staggering. We urge the committee to provide emphasis for the application of endoscopy to digestive disease research.

Again, I want to thank you, Mr. Chairman, and the members of this committee for your clear interest in and support of NIH and NIADDK. We feel that with your continued leadership and direction the advancements being achieved in digestive diseases within NIADDK will receive a forward thrust. ASGE feels that endoscopy can play a signicant role in this process.

Thank you.

STATEMENT OF DONNA THIEL, DIRECTOR, DEAN THIEL FOUNDATION

Senator ANDREWS. Our next witness is Donna Thiel, director of the Dean Thiel Foundation.

It's good to have you here.

Ms. THIEL. Thank you.

Mr. Chairman, I am Donna Thiel. I'm an attorney here in Washington, but today I'm speaking on behalf of the Dean Thiel Foundation established in 1971 by my family in memory of my brother, Dean, who died at the age of 4 of cirrhosis of the liver caused by biliary atresia.

At that time, liver transplantation was not considered a viable option, and Dean suffered daily from itching, fractured bones, multiple hospitalizations, and several surgical operations. We hoped and prayed that researchers would find a cure. The heartache we shared as a family is indescribable but understandable.

Upon Dean's death, we learned that no national effort existed to address the many problems that we, like other families, faced. Moreover, there was very little information available about liver diseases or about the number of children and adults who suffered from them.

Today infants, mothers, fathers, families suffering from incurable liver diseases now have hope for survival. The discovery through research of the drug cyclosporin and the improvement of techniques of liver transplant surgery has changed a previously dismal picture for victims of fatal liver diseases.

However, with these advances have come new problems and frustrations. As anyone whose loved one has suffered with any disease will attest, preserving a life cannot be measured in dollars, and yet the cost of liver transplants is forcing individuals to make daily pleas for funds to pay for this procedure.

The Dean Thiel Foundation asks you to assess the need of the victims of liver disease. There is extreme urgency to make decisions about the future health of our Nation. Transplants are a bandaid solution to the enormous problem of liver disease. We must increase our efforts to find the answers by employing more brilliant young investigators to join the search. We can't afford to waste the enthusiasm of young investigators by saying we can't support their research and training.

The Dean Thiel Foundation asks you to make a critical investment now to accelerate the search by funding NIADDK at the level of $475 million.

We also ask you to support digestive disease centers to enhance research efforts. We need help to know how effective or ineffective our programs addressing digestive diseases are by establishing an epidemiological data collection system.

Thank you for giving me this opportunity to share our concerns with you. We've come a long way, but there's a long way to go.

PREPARED STATEMENT

Senator ANDREWS. Thank you for an excellent statement, and for the good work your Foundation is doing.

Ms. THIEL. Thank you.

[The statement follows:]

STATEMENT OF DONNA THIEL

Mr. Chairman and members of the subcommittee, I welcome this opportunity to share my concerns with you and would like to make a few brief comments.

I am Donna Thiel, an attorney here in Washington. Today I'm speaking on behalf of the Dean Thiel Foundation, established in 1971 by my family, in memory of my brother, Dean, who died at the age of 4 of cirrhosis of the liver caused by biliary atresia.

At that time, liver transplantation was not considered a viable option, and Dean suffered daily from unrelenting itching, fractures of his hips and legs, multiple hospitalizations, and several surgical operations. The heartache we shared as a family is indescribable. Upon Dean's death, we were appalled to learn that no national effort existed to address the many problems that we, and others like us, faced. The Dean Thiel Foundation was the first to initiate a national effort to call attention to this sadly neglected area of need.

The public awareness of the liver and the need for increased support for liver research is beginning to have an impact. Americans are much more informed about their livers and the vital role this remarkable organ plays in our lives. They have learned that children, too, can die of liver disease—not just alcoholics.

Daily, the media is calling attention to the need for liver donors—primarily for children—even though just as many, if nor more adults need liver transplants than children. Infants, mothers, and fathers suffering from incurable liver diseases now have hope for survival. The discovery through research of the drug cyclosporin and the improvement of techniques of retrieving, preserving, and implanting livers has changed a previously dismal picture for victims of fatal liver diseases. However, with these advances have come new problems and frustrations. The cost of liver transplants is forcing individuals to make daily pleas for funds to pay for this procedure. Families crushed by the burden of medical costs are seeking thousands of dollars.

As new transplant centers are established the need for donors and dollars will increase dramatically. The human cry will be deafening—but will it fall on deaf ears? The Dean Thiel Foundation asks you to assess the need and evaluate the benefits to be derived from saving the lives of thousands of victims of liver disease. An investment in preserving a life cannot be measured in dollars. The potential for a productive life is there. We could be saving the life of another Einstein, or Beethoven, or Schwietzer. Time is running out on many who suffer from liver disease. There is extreme urgency to make decisions about the future health of our Nation. Transplants are a bandaid solution to the enormous problem of liver disease. We must increase our efforts to find the answers by employing more brilliant young investigators to join the search. We can't afford to waste the enthusiasm of young investigators by saying we can't support their research and training.

The Dean Thiel Foundation asks you to make a critical investment now to accelerate the search by funding NIADDK at the level of $473 million. We also ask you to support digestive diseases centers to enhance research efforts. We need help to know how effective or ineffective our programs addressing digestive diseases are by establishing an epidemiological data collection system. And finally we ask you for continued support for the Digestive Diseases Advisory Board, that has significantly increased efforts to solve many of the problems of digestive diseases..

Thank you for giving me this opportunity to share our concerns. We have come a long way, but have so much more to do.

STATEMENT OF THELMA KING THIEL, VICE CHAIRMAN AND EXECUTIVE DIRECTOR OF AMERICAN LIVER FOUNDATION

Senator ANDREWS. We will next hear from Thelma King Thiel, the vice chairman and executive director of the American Liver Foundation.

Ms. THIEL. Mr. Chairman, thank you very much for inviting me.

Senator ANDREWS. Welcome to the subcommittee.

Ms. THIEL. I happen to be the very proud mother of the lady that just spoke.

Senator ANDREWS. She's done quite well. And having a lady lawyer as my daughter, I know exactly how you feel.

Ms. THIEL. I'm delighted to be here today. And I am Thelma King Thiel. I am the executive director and the vice chairman of the American Liver Foundation. I am also serving on the National Digestive Diseases Advisory Board and as an adviser to the National Digestive Diseases Clearinghouse.

The past year truly has been a milestone for advances in liver research.

The hepatitis B vaccine, available since last June, has the potential for saving millions of lives and reducing health care costs in this country dramatically. The economic burden of this disease—which is only 1 of 100 liver diseases—is estimated at $1 million a day for the 200,000 cases that occur each year.

This major breakthrough in research came through the combined efforts of a few brilliant scientists: Drs. Blumberg, Prince, Krugman, and Hilleman. The benefits of this investment made by NIH in the work of these men, in terms of the potential for saving lives, is immeasurable. The task that lies ahead of us is to turn this potential into reality. The American Liver Foundation is playing a major role in this effort by informing the public about the hazards of hepatitis B infection and its prevention.

The second exciting milestone, the improved success rate of liver transplants, has given hope to thousands of victims of a host of presently incurable liver diseases. The untiring efforts of an exceptional surgeon, Dr. Starzl, supported by NIH grants, and the discovery of the drug cyclosporin, developed by private industry, have made medical history. Again we are describing the efforts of a few dedicated researchers.

Tragically, the number of brilliant minds committed to seeking answers to liver diseases has been extremely limited due to the low level of funding for research into the mysteries of the liver, the most complex organ in our bodies. The attrition of young investigators in the field of liver research is alarming.

If major advances like the development of the vaccine and the transplants are to continue, we must entice bright, young, enthusiastic scientists to join our effort. The only way we can do this is by supporting their efforts on our behalf.

Liver research, all digestive disease research, has just begun to generate public support. These unpopular and often maligned diseases have received little emphasis and less support from a public that is still uncomfortable about mentioning them.

We have come a long way to recover the time lost, but we have to work very hard to increase our efforts. To bring digestive diseases research up to a par with more familiar diseases, the American Liver Foundation strongly recommends that NIADDK receive no less than $475 million in fiscal year 1984, with at least $80.5 million allotted for digestive diseases and nutrition.

Support for digestive disease research centers is critical to facilitate the technology transfer and enhance research advances and opportunities. The recent proliferation of liver transplant centers highlights the need for these multifaceted digestive disease centers.

ALF also recommends that an epidemiological data system be established. The difficulties in collecting data to identify digestive disease problems and trends, to measure the impact of treatments and management techniques literally has the digestive disease community hamstrung in their attempts to identify and evaluate DD problems and progress.

We have made great steps forward with extremely limited resources. We must accelerate the process to attain our goal of saving lives and reducing the agony of illness caused by digestive diseases.

Thank you very much.

PREPARED STATEMENT

Senator ANDREWS. Thank you very much.

[The statement follows:]

STATEMENT OF THELMA KING THIEL

I am Thelma King Thiel, executive director and vice chairman of the American Liver Foundation, vice chairman of the National Digestive Diseases Advisory Board, and an advisor to the National Digestive Diseases Education and Information Clearinghouse.

The past year truly has been a milestone for advances in liver research.

The hepatitis B vaccine, available since last June, has the potential for saving millions of lives and reducing health care costs in this country dramatically. The economic burden of this disease is estimated at $1 million a day for the 200,000 cases that occur each year.

This major breakthrough in liver research came about through the combined efforts of a few brilliant scientists: Dr. Blumberg, Dr. Prince, Dr. Krugman, and Dr. Hilleman. The benefits of this investment made by NIH in the work of these men, in terms of the potential for saving lives, is immeasurable. The task that lies ahead of us is to turn this potential into reality. The American Liver Foundation is playing a major role in this effort by informing the public about the hazards of hepatitis B infection and its prevention.

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Tragically, the number of brilliant minds committed to seeking answers to liver diseases has been extremely limited due to the low level of funding for research into the mysteries of the most complex organ in our bodies. The attrition of young investigators in the field of liver research is alarming. If major advances like the development of the vaccine and improved success rate of liver transplants are to continue, we must entice more bright, young, enthusiastic scientists to join our effort. The only way we can do this is by providing an adequate level of support for their efforts on our behalf.

Liver research—all digestive disease research, has just begun to generate support for the general public. These unpopular and often maligned diseases have received little emphasis and less support from a public that is still uncomfortable about mentioning them.

Ladies and gentlemen, we have a long way to go to recover the time lost by suppression and ignorance of these devastating diseases.

To bring digestive diseases research up to par with other more familiar diseases, the American Liver Foundation recommends that NIADDK receive no less than $473 million in fiscal year 1984, with at least $80.5 million allotted for digestive diseases and nutrition.

Support for DD research centers is critical to facilitate the technology transfer and enhance research advances and opportunities. The recent proliferation of liver transplant centers highlights the need for these multifaceted DD centers.

ALF also recommends that an epidemiological data system be established. The difficulties in collecting data to identify digestive disease problems and trends, to measure impact of treatments and management techniques literally has the DD community hamstrung in their attempts to identify and evaluate DD problems and progress.

We also recommend appropriations for the DD Advisory Board. The increased emphasis on digestive diseases and the cooperation between NIH and other Government offices through the efforts of the Digestive Diseases Advisory Board has been significant. These benefits warrant support for continuation of this board.

We have made great steps forward with extremely limited resources. We must accelerate the process to attain our goal of saving lives and reducing the agony of illness caused by digestive diseases.

I thank you for giving me the opportunity to share our concerns.

STATEMENT OF DR. C. W. LEGERTON, CHAIRMAN OF THE COMMITTEE ON PUBLIC POLICY OF THE AMERICAN GASTROENTEROLOGICAL ASSOCIATION

Senator ANDREWS. Our next witness will be Dr. C. W. Legerton, who is the chairman of the committee on public policy of the American Gastroenterological Association.

Dr. LEGERTON. That's correct, Senator. Thank you.

Senator ANDREWS. One of my daughters is a lawyer and the other daughter is in her second year of medical school; I know about those tongue-twisting phrases.

Dr. LEGERTON. You did very well with that word, which is a difficult one. And I appreciate the opportunity to make some comments in testimony.

I represent the American Gastroenterological Association, Senator, in cooperation with other organizations that are concerned with digestive diseases research. We recommend regarding appropriations for fiscal year 1984 that the Appropriations Committees support funding for the following programs:

First, that the National Institute of Arthritis, Diabetes, Digestive, and Kidney Diseases be funded at a level of at least $475 million;

Second, that various programs of the NIADDK, likely to be made law this year, be supported with appropriated funds. These are four things: Digestive Diseases Advisory Board, digestive diseases centers, development of a digestive diseases epidemiological data program, and a digestive diseases education and information clearinghouse.

And third, we recommend, Senator, that the National Institutes of Health itself be supported sufficiently strongly to provide for 5,000 research grants in fiscal year 1984 without decreasing other programs to provide for such funds.

With the help of this committee and others, we have made great strides in research in digestive diseases, and the Congress has been of great value to us in this. Four very brief examples:

Our understanding of certain liver diseases has advanced markedly. The survival rate in liver implantation, as Ms. Thiel has just commented on, has been greatly improved. We now have very potent medications for the healing of peptic ulcer diseases, and we have made remarkable strides in our understanding of cancer of the liver and the large intestine.

Many of these breakthroughs, and others, are largely dependent upon support given by this subcommittee and others, and we thoroughly appreciate it.

Senator Andrews, if I may digress for a moment from my formal testimony, I'd like to comment about the need for funding of digestive disease centers.

Several weeks ago the administration and NIH witnesses appeared before this committee indicating that the NIH would cease its support of new and continued renewal centers programs. You've seen these documents; there's no need for me to bring out the list. But it specifically regards cancer centers, arthritis centers, diabetes centers, and others.

As you know, both the Senate and the House versions of the authorizations bill for biomedical research contain new authorities for digestive disease centers. We who are daily involved with digestive diseases are seriously concerned with the new administration initiative to stop such centers. We believe that new centers are not only desirable, but they are absolutely necessary if we are going to move forward in digestive diseases. And, therefore, we are in concert with the NIADDK that these present centers should be funded, and that new centers would also have the opportunity to be funded.

I hope I've made your 3 minutes. I appreciate it very much. Thank you, sir.

PREPARED STATEMENT

Senator ANDREWS. You have done very well. And you used the wisdom of the experienced witness where you realized that your full statement will be included in the record, and then you get a little more in by encapsulating it.

Dr. LEGERTON. Thank you, sir.

Senator ANDREWS. Thank you for your statement.

[The statement follows:]

STATEMENT OF DR. C. W. LEGERTON

I am Clarence W. Legerton, M.D., Professor of Medicine at the Medical University of South Carolina at Charleston. I represent the American Gastroenterological Association, which has over 4,000 physician members, who are concerned with the improvement of patient care and research in the field of digestive diseases.

Mr. Chairman, you and the Members of this committee have heard for the last several years a team of lay and professional persons concerned with digestive diseases give testimony regarding the excellent research opportunities now available in the field of digestive diseases, as well as what your continuous support has meant to the field.

Later in this testimony I will indicate some of the remarkable research opportunities that lie before us. However, before doing that, I would make a special plea to this subcommittee to support several legislative items which are likely to be passed by the Congress this year, prior to the time that your mark-up in the Subcommittee on Appropriations will occur.

First, it is quite likely that the Congress will see fit to extend the life of the Digestive Diseases Advisory Board. That Board will again need its yearly appropriation to continue its excellent work.

Second, it is quite likely that the Congress will agree to the establishment of digestive diseases research centers. The American Gastroenterological Association has indicated to the authorizing committees its support for these centers.

Third it is likely that the Congress will agree to an epidemiological data program for digestive diseases established within the National Institute of Arthritis, Diabetes and Digestive and Kidney Diseases.

Fourth, it is necessary to continue the work of the Education and Information Clearinghouse for Digestive Diseases, which is also based at that Institute.

You will recall, Mr. Chairman, that late last year a bill regarding NIH authorizations almost completed passage in both the House and the Senate. You should know that the House bill contained all of the above authorities, when it was passed in the middle of last year. In the Senate bill, the bill carried the authority for the continuation of the life of the Digestive

Diseases Advisory Board, and excellent bill report language was given in support of centers and the epidemiological data program. We firmly believe that by the time the NIH authorizations are enacted into law this year that all four of the above items will be authorized. If that occurs, Mr. Chairman, we are hopeful that you will agree to providing the necessary funding for them.

Now may I discuss briefly some of the research opportunities that are of great interest to us? Always in the past when this committee has learned of opportunities, it has urged on the research community by appropriate bill report language, and we hope that this year you will do the same.

Some examples are:

The survival rate in liver transplantation has been greatly increased by improvements in medical management and in surgery, and by the use of a new immunosuppressant, Cyclosporin A, which helps control the body's tendency to reject the graft. We have learned much about the liver and its importance in specific disorders; for example, after liver transplantation in patients with Wilson's disease, the neurological symptoms are arrested, and in some cases even reversed.

The improved survival of patients with liver transplantation should enable us to learn more about the part the liver plays in disorders in which the pathology appears to be primarily in the liver itself, such as primary biliary cirrhosis.

We have found that the DNA of the virus of Hepatitis B is incorporated into the nuclear material of liver cells in some patients who have had chronic active hepatitis for several years. This has also been found in patients with cancer of the liver, strongly suggesting a relationship between chronic active hepatitis and cancer. This relationship is supported by epidemiological studies.

We are identifying hormones in the digestive tract that control its major functions of motility, secretion and digestion. Similar hormone. have been found in the brain and further studies should provide new insight into the relationship between the nervous system and the digestive tract.

Specific nutrient requirements, particularly for minerals, are being identified by studying patients who are kept alive solely by parenteral nutrition. We have made advances in certain bone diseases, which result in bone fractures, by studies on new vitamin D metabolites.

Cimetidine has proved to be an effective treatment for peptic ulcer. Ranitidine, a similar drug with perhaps fewer side effects, will soon be on the market and other drugs which act in a similar fashion to reduce gastric acid secretion are under active investigation. In addition, we have identified another form of treatment for peptic ulcer that works by covering the ulcerated area and protecting it so that it can heal.

We can move forward in the study of new peptide hormones which we have recently discovered, determining how they influence secretion, digestion, and movement of the digestive tract.

We have learned much in recent years about cholesterol gallstones; and about a quarter of gallstones contain primarily calcium and pigment. By further characterizing these components and their interrelationships we should learn much about the pathogenesis of such gallstones.

We are continuing multidisciplinary research on a development of techniques to enable us to obtain pancreatic tissue from patients with pancreatitis. Analysis of such tissues would help to elucidate the specific pathogenesis of types of pancreatitis that appear to have different causes, such as alcohol, biliary tract disorders, and hyperlipidemia. Knowledge of pathogenesis would lead directly to treatment advances.

We need to carry out further studies to define the specific receptors on the intestinal mucosal surface of the host and the molecular mechanisms which mediate toxin and microbial adherence in infectious diarrheas. Once we do this, it may be possible to modify them or block them with an innocuous analogue. In such a way we could prevent toxins from acting on the mucosa of the digestive tract and thus prevent illness.

Mr. Chairman, we thank you for the opportunity that you have given for us to appear yet another time in support of digestive diseases appropriations. We are very grateful to you for all the work that you have done in the past.

Along with other groups which are concerned about funding of the National Institute of Arthritis, Diabetes and Digestive and Kidney Diseases, we recommend for FY 1984 that $475 million be appropriated for this institute.

Though this is the first time that I, myself, have testified before your committee, I have learned from Dr. John Sessions, who was the very able spokesperson for the American Gastroenterological Association before this committee, of your great courtesy and of your continuous support. All of us, in our Association, are deeply grateful to you for that.

Thank you. If you have any questions, I would be pleased to answer them.

STATEMENT OF MARY F. BERRY, PH. D., ON BEHALF OF THE LUPUS FOUNDATION OF AMERICA

Senator ANDREWS. Our next witness will be Dr. Mary Berry of the Lupus Foundation of America.

Dr. Berry, it's nice to have you here.

Dr. BERRY. Good morning, Senator. It's nice to see you.

I'll try not to take up more than 3 minutes, or less than that.

Senator, I've spent a lot of time in the past up here before this subcommitte arguing the case for education programs when I ran education in HEW. I spent about 3 years doing that. But today I'm up here for a different reason.

And I understand that my statement will be inserted in the record.

Senator ANDREWS. It certainly will.

Dr. BERRY. So with that objective, I will simply summarize.

I'm here to call attention to a matter of deep personal concern to me, the Lupus erythematosus disease. It is a chronic disease of the connective tissue. It strikes down, unfortunately, a disproportionate number of women, young women of child-bearing age, people who are just starting out college, a lot of them, as my niece was when she died from Lupus about 3 years ago at the age of 20.

In fact, scientists do not know what causes the disease which strikes women, 70 percent, and a disproportionate number within the female group were black women, for some reason that we don't know.

About a half a million people suffer from it, and there are about 50,000 new cases a year.

There has been some progress in trying to identify the causes of the disease, in fact due to the efforts of this subcommittee and the Subcommittee on HHS and Labor on the House side. As a matter of fact, there was a report which the House subcommittee asked for last year from NIH to see what they're doing about Lupus, and it asked them to keep it up-to-date and report to that subcommittee on the progress that is being made and the funding.

And there was some slight increase in the amount of funding that went to Lupus research in 1982, but in fact, Senator, we need to have more targeted research to try to identify the causes of this disease, which is so debilitating. Even when people do not die from it within 5 years they lead isolated lives filled with tension and a lot of stress on their families and enormous pain and suffering, as with many other diseases.

I know you have a lot of matters to give your time and attention to, and that people are concerned about research in a lot of areas. But we know that if the subcommittee pays no attention to a specific area, researchers who are out there who are coming along or who are deciding what fields to go into will decide, "Well, maybe that's not an area I should pick; there won't be any funding for what I want to do there." And research is expensive.

So all I really want to do is to ask you, while you keep everybody else's problems in mind, please don't forget about the victims of Lupus.

Thank you, Mr. Chairman.

Senator ANDREWS. You said it very well, Doctor. It's nice to have you here.

Dr. BERRY. Thank you.

[The statement follows:]

STATEMENT OF MARY F. BERRY

Mr. Chairman and members of the subcommittee, I am pleased to be here before you today. You may recall that I have sat before this subcommittee before—usually to plead the case for education. But I am here today with a different purpose. I am here to call attention to something that is of deep personal concern to me and to millions like me who have lost family and loved ones to a disease called Lupus erythematosus.

Lupus is a chronic disease of the connective tissue. It can affect any number of tissue and organ system, including the heart, kidney, nervous system, joints, and skin. The disease most frequently manifests itself as arthritis, fever, skin rash, pleurisy, and kidney and heart disease.

Scientists are still not sure what causes the disease, but research leads us to believe that it stems from the body's failure to recognize its own healthy cells. What happens is that the body reacts to its own cells as though they are foreign substances. In other words, the body's immune system turns against itself.

Mr. Chairman, more than half a million people suffer from Lupus and more than 50,000 new cases are diagnosed each year. More than 70 percent of the victims are women, usually in their childbearing years. For some reason, the disease is most prevelant in black women. According to NIH, Lupus strikes 1 in 1,000 women and 1 of every 245 black women.

The victims of Lupus, no matter who they are, face a long siege of painful illness that all too frequently ends in death.

Mr. Chairman, with this subcommittee's support over the last several years, we have been able to make some progress agaisnt this disease. Thirty years ago, fewer than half of the Lupus patients survived more than 4 years after diagnosis. Now, about 95 percent of the Lupus patients survive 5 years or more.

That is progress—but far too little as far as I am concerned. We are still unable to cure the disease, let alone preventing it. As a result, hundreds of thousands of people, most of them young women, are prevented from leading satisfying and useful lives. Instead, they and their families can look forward to prolonged isolation and misery while the disease takes it course.

Mr. Chairman, research on Lupus is supported primarily through the Arthritis Institute and the National Institute of Allergy and Infectious Diseases. With this subcommittee's support, these institutes have funded projects that have helped shed some light on Lupus. They have found, for example, that genetic factors play a role in the development of Lupus and that there is a moderate tendency for Lupus to occur in more than one family member.

In another study, it was shown that female hormones accelerate Lupus, while male hormones suppress it. The hope is that someday Lupus might be treated by correcting the sex hormone imbalance.

Mr. Chairman, I realize this subcommittee has its hands full. You are facing many tough issues—some more obvious than others. I know, too, that this subcommittee understands how vital medical research is to the long-term health and well-being of the country.

I encourage you to continue your support for Lupus research and for NIH in general.

Thank you, Mr. Chairman.

STATEMENT OF J. WILLIAM FIELDING, M.D., PRESIDENT, AMERICAN ACADEMY OF ORTHOPAEDIC SURGEONS

Senator **ANDREWS**. Our next witness will be Dr. J. William Fielding, the president of the American Academy of Orthopaedic Surgeons.

Dr. **FIELDING**. Good morning, Senator.

Senator **ANDREWS**. Good morning. Welcome to the committee. Let me assure you that your statement will be included in full in the record, and you can summarize it in any way you wish.

Dr. **FIELDING**. My name is Joseph William Fielding, and I'm president of the American Academy of Orthopaedic Surgeons. I practice orthopaedic surgery in the State of New York, in New York City, and, as such, I have the opportunity to see a great number of people with disabling diseases of the musculoskeletal system and to treat them.

I'm very pleased today to have this opportunity to be able to speak to you concerning some of these problems.

There are over 37 million Americans afflicted with arthritis and musculoskeletal diseases, and as the population of this country grows older, by the year 2000, approximately 30 percent of the population will be 65 years of age or older. And in this age range it's understandable that problems with the joints develop perhaps more rapidly and more severely than in individuals in the younger age group.

There are many appliances that have been developed over the past few years which have provided tremendous relief for individuals with disabling pain: an individual has difficulty walking, they can't get to the post office; they can't get around at home because their hips are so painful they can't move them. Not only can they not move them, but the joint motion is so restricted that it's almost impossible for them to do simple things: put on their shoes, put on their stockings, and so forth.

Now, devices have been developed by orthopaedic surgeons through research, not only on the disease itself but also on the materials used in the production of these devices which have relieved so many people with disabling disorders. The hip is probably the best example, and surgical procedures on the hip have a predictably high degree of success, especially with the advancement that has taken place in the last few years.

But others are being developed, too, for problems with the elbow. A stiff elbow is a dreadful thing: you can't hold your glasses as you're holding yours now.

Senator ANDREWS. They call it tennis elbow, so that they can relate themselves with sports——

Dr. FIELDING. Senator, I'm sure that as time goes on they will develop devices that will not only allow you to play tennis better but also perhaps win a few championships.

Senator ANDREWS. I'm afraid that takes coordination which I probably don't have.

But in the House, in the years I served over there, one of my colleagues and good friends from your State, Jim Delaney, had a tough time getting around, and he had two hip replacements and got back to walking full tilt. You did well for my colleague.

Dr. FIELDING. And we want to do well for America. And I think the only way we can do that is by perhaps having you provide at least $475 million to the NIADDKK grants as soon as possible, so that some of this research can proceed, not only in the elbow but also in the shoulder, the foot and the ankle, and especially in the knee.

These disorders are disabling, they're painful, they're limiting: a person can't work, they can't enjoy themselves, they can't grow old gracefully.

With this research, and with the money to fund it, people who are in this room today who may have these problems can live productive lives.

I see a lot of patients in my practice now that were cripples before the surgery, and they're now restored to—I won't say "normalcy," but at least comfort, and can provide input into things that they couldn't provide before.

I'd be happy to answer any questions that you might have.

PREPARED STATEMENT

Senator ANDREWS. I think you have already.

Thanks for an excellent statement. It's good to have you here.

Dr. FIELDING. Thank you, sir.

[The statement follows:]

STATEMENT OF J. WILLIAM FIELDING, M.D.

Mr. Chairman and Members of the Committee, I am William Fielding, M.D., President of the American Academy of Orthopaedic Surgeons, and a practicing physician in New York City.

I am pleased to have this opportunity to appear before you today to present the Academy's position on the need for continued, and hopefully, expanded funding of research on the musculoskeletal system.

The musculoskeletal system of the body, includes those anatomic elements of structural support essential to function of the body, as a whole. This includes, for example, bones, joints, muscles, ligaments, and tendons.

Mr. Chairman, over 37 million Americans are afflicted with arthritis and musculoskeletal diseases. Although such health problems are not fatal, they cause pain and widespread disability. Of all illnesses, musculoskeletal diseases, including arthritis, rank second in overall economic impact, costing society over $30 billion annually in terms of medical expenses, disability payments and lost earning power.

The diseases and disorders I am referring to are:

- Arthritis, which is the leading cause of restriction of mobility;
- Joint disorders, which affect more than 15 percent of our population;
- Birth defects and inherited disorders, which often lead to permanent handicaps, and a decreased life expectancy; and

- Hip and spine fractures and osteoporosis, which are common in our elderly population and which account for a substantial cost to the Medicare program.

These problems and their economic impact can be expected to increase as our population gets older.

During the past five years, a large number of individuals have benefited from new knowledge and techniques made possible by musculoskeletal research funded in part by the National Institute of Arthritis, Diabetes, and Digestive and Kidney Diseases. For example,

- Total joint replacement, including design, materials, and revisions of failed implants;

- The use of electricity and electromagnetic fields on healing of fractures, bone regeneration and osteoporosis;

- Whole joint and muscle transplanation; and

- Fracture fixation, including improved materials which lessen hospital stay and patient morbidity.

Although we have learned much about musculoskeletal diseases and disorders and although we have restored people to productive life, we must continue our research in order to ultimately undertake prevention programs. It is only through prevention that we can give hope to our society.

There are a number of promising areas of musculoskeletal research which, with continued research funding, will contribute to earlier detection, better treatment, and hopefully prevention. For example,

- Research on bone diseases which weaken the skeletal support mechanism to determine the effects of genetic predisposition, diet, hormones, and environment on the severity and incidences of these diseases;

- Research on the causes of osteoarthritis, its pathophysiology, and better methods of improving function in the diseased joint to include cartilage grafts and control of cartilage remodeling;

- Research on joint injuries that often lead to premature arthritis;

- Research on the pathophysiology of back pain in order to provide a rational approach to decrease the impact of this major disorder on society;

- Research on the cellular effects of electrical currents, identifying areas of application in restoration of musculoskeletal function such as fracture healing, bone, cartilage, nerve and muscle growth.

Mr. Chairman, the over 65 population will increase by 30 percent by the year 2000, and this increase will bring with it a myriad of chronic and disabling disorders. A greater demand for health services, medications, devices, hospitalization, and nursing home admissions will accompany the graying America. This, as all of you know, will place an enormous burden on the Medicare program. Today's problems of cost containment will appear insignificant when compared to the problems we will face in the 1990's. We can minimize the burden of those future problems, only by taking the necessary step now to provide for an adequate investment in all aspects of biomedical research -- basic, applied, training, and technology transfer.

The NIH budget for 1984 does not call for a balanced investment of resources. For example, the budget proposes to eliminate funding for a number of research centers. These research centers play a major role in helping NIH carry out its assigned mission. The centers, such as the multipurpose arthritis centers, conduct basic research, as well as applied research and technology transfer. It is often through the centers that the fruits of research reach the patient population afflicted with a particular disease.

Mr. Chairman and Members of the Committee, we fully appreciate the difficult fiscal conditions under which you are operating, but we believe that in spite of these constraints, the government must provide for the sound health of its citizens today and into the future.

It is with this in mind that we respectfully urge this Committee to provide $475 million for the National Institute of Arthritis, Diabetes, and Digestive and Kidney Diseases in fiscal year 1984. We believe this amount will permit restoration of funding for centers, as well as full funding of regular research grants.

On behalf of the 10,000 members of the American Academy of Orthopaedic Surgeons, I want to thank you for your past interest and support of biomedical research, and for this opportunity to testify before you today.

I will be happy to answer any questions.

STATEMENT OF ARLENE PESSAR, R.N., EXECUTIVE DIRECTOR, DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA

Senator ANDREWS. Our next witness will be Arlene Pessar, a registered nurse who is the executive director of the Dystrophic Epidermolysis Bullosa Research Association of America.

Ms. PESSAR. Pretty good.

Senator ANDREWS. OK. Glad to have you here.

Ms. PESSAR. Thank you.

I am Arlene Pessar, founder and executive director of the Dystrophic Epidermolysis Bullosa Research Association, a national voluntary organization founded 3 years ago by a small group of parents whose children have epidermolysis bullosa, an incurable, life-threatening group of genetic skin disorders.

This is Cal Larsen and Cal and Cliff Bennett-Haley. Cal is from Silver Spring and the Bennett-Haley boys came all the way from South Carolina to be with us today. These young men have lived with the problems directly related to epidermolysis bullosa since their birth.

Last year we appeared before the subcommittee for the first time to talk with you about epidermolysis bullosa and to share our views regarding the urgent need to increase Federal funding for research into this disease.

This year we are grateful to have the opportunity to talk to you again about the President's budget for NIADDK, the Institute primarily responsible for skin disease research.

My full testimony has been submitted and my comments will be limited.

Before we make any specific recommendations, I would first like to publicly express our deep appreciation and thanks to the members of this committee for the consideration and interest they have shown about epidermolysis bullosa.

Although the words epidermolysis bullosa first appeared in the medical literature in 1869, until 2 years ago it was considered an enigma among the academic and scientific community. This past year, however, mainly because of the concern shown by members of this committee and the House committee and their staff, more attention has been focused on EB. But because of drastic cutbacks in the NIADDK budget, we fear that the progress we have made this past year will be lost and once again research related to EB will be severely retarded.

The implications of this serious situation can readily be appreciated by looking at the numbers of patients with epidermolysis bullosa from the United States migrating to a private clinic in West Germany which offers a cure for EB, but employing an unproven, secretive, and expensive method of therapy.

In December a meeting was held with the National Institutes of Health, with several U.S. dermatologists and the West German team to evaluate the results of this miraculous treatment. Although the NIH scientists "could find no evidence for any unique therapeutic feature" in the program, patients are still running to Germany.

To date the number of patients treated at this clinic is over 150, and close to $3 million in publicly donated funds has been raised to pay for these trips. The fact that such a desperate situation exists is both a commentary on the nature of the disease and upon the sad fate of many patients with rare diseases in our society.

I know that the only hope for my son, who is 12½ and suffers from this disease, and the other children and young adults who suffer from EB will depend on advances in basic science. This can only be achieved through an expansion of NIH funding of skin biology and other programs. But I also know that the needs of these patients and their families must be addressed in a more immediate and creative fashion.

Ultimately I believe the real answers to EB require a multidisciplinary approach and inter-institute coordination on this disease and other disorders affecting the dermal-epidermal junction of the skin.

In summary I would like to make two recommendations:

One, that Congress increase the NIADDK budget to $475 million so we can continue to fund its existing research programs;

And two, that specific language be included in the final appropriation bill that directs the NIH, specifically the NIADDK, to strengthen and expand its research programs in EB and EB-related diseases.

I thank you for giving me this opportunity to present our views. I hope this committee looks favorably upon our recommendations this year, as they have in the past.

Thank you.

PREPARED STATEMENTS

Senator ANDREWS. Thank you very much for an excellent statement. And thanks to you young people for coming along with her.

Your statement will be included in the record at this point along with other statements submitted for the record on appropriations for the National Institute of Arthritis, Diabetes, Digestive, and Kidney Diseases.

[The statements follow:]

Statement of Arlene Pessar

My name is Arlene Pessar. I am the Executive Director of the Dystrophic Epidermolysis Bullosa Research Association (D.E.B.R.A.), a national voluntary organization founded three years ago by a small group of parents whose children suffer from Epidermolysis Bullosa (EB). My son, Eric, is 12½ years and has lived his entire life with the pain, stigma and many of the medical problems directly related to this life-threatening genetic disease.

Last year members of our group testified before this Committee for the first time. We addressed some issues which have been a source of great concern to us, specifically regarding the need for increased federal support to further the knowledge and understanding of this complex group of disorders.

Today we are here again. Before we make our specific recommendations, I would first like to publicly express our deep appreciation and thanks to this Subcommittee for the consideration and interest they have shown about EB. Although EB was first described in the medical literature in 1869, until two years ago it was considered an enigma among the academic and scientific community, the public and the government. This year, however, mainly because of the concern shown by members of this subcommittee and their legislative aides, more attention has been focused on EB by representatives at NIH, especially NIADDK. And for this we are eternally grateful. But despite the added attention, unfortunately the picture for EB has not changed, and the future for children born with EB is still very grim. (I would like to make part of the record a letter from Dr. and Mrs. Paul Van Dyke to Senator Randolph of West Virginia sharing their tragedy about this terrible affliction.)

And once again we appeal to this Committee and ask that stronger direction be given to the NIH so that research to find improved methods for diagnosis, effective treatment, recognition of the carriers, and ultimately prevention of both the disease and its complications is carried out.

Like most people, unless you have personally been touched by EB it is unlikely that you are familiar with the disease, its complications and its often painfully fatal course. I, therefore, would like to briefly review what EB is. I have prepared a one-page sheet which outlines some of the known facts about EB.

EB is a group of incurable, life-threatening, inherited diseases that cause blistering and destruction of the body's largest organ: the skin. In its mildest forms the blisters may be confined to the hands and feet. In its severest forms, the entire body is affected and simple every day chores, such as eating, swallowing, or even breathing, can cause severe pain and massive damage. In the dystrophic and junctional forms, the mucous membranes of the mouth, esophagus, gastrointestinal, genitourinary and respiratory tracts are involved. Nutritional complications are common and include malnutrition, dehydration, iron deficiency anemia, malabsorption and excessive protein and fluid loss.

EB has been referred to as "the disease that baffles doctors" because so little is known about its causes, its treatment and its prevention. Because it is congenital, it results in a life of restricted activity, disability and prolonged suffering for both the victim and the family. In addition, repeated hospitalizations and extensive nursing, medical and surgical intervention make it a great economic burden to the family and to society. The average cost of home care for children afflicted with EB exceeds $10,000 - $15,000 annually. In the absence of adequate medical coverage, these costs can deplete a family's resources, especially since the expenses go on year after year. Because EB is an "orphan" disease many agencies are unfamiliar with it, and consequently many of these children are found ineligible for services under the Crippled Children's, Developmental Disability, and Medicaid programs.

Last year we spoke to this Committee about the mass migration of children suffering from EB to a private clinic in West Germany offering a "cure" for EB, but employing unproven, secret, and expensive methods of therapy. In December, a meeting was held at the NIH with several U.S. dermatologists and the West German group to evaluate the results of this program. The conclusions drawn from the discussions were that the U.S. scientists "could find no evidence for any unique therapeutic feature... and could lend no legitimacy or endorsement to Mr. Kozak's treatment and recommend no support of its further study". A complete report of this meeting has been published in the April 1983 issue of the Journal of the American Academy of Dermatology. Despite the skepticism by these scientists and most American physicians, the saga continues. Only presently the number of patients going to Germany has reached the hundreds and the amounts of publicly donated funds is over $3 million. The fact that such a desperate situation exists is both a commentary on the nature of the disease, and upon the sad fate of many patients with chronic diseases in our society.

Last year our recommendation to this Committee included Federal support for a multi-disciplinary center for EB. We realize now that in times of tight money this request may have been untimely. But because we so strongly believe that a comprehensive approach to research is the best way to achieve a transfer of technology, disseminate better information and state-of-the-art care to the practicing physician and the patients, I am pleased to tell you that our organization has taken on the challenge of funding one such center. Just a few weeks ago, I presented Dr. Eugene Bauer and his colleagues of the Division of Dermatology at Washington University School of Medicine in St. Louis with

D.E.B.R.A.'s first donation of $25,000 towards this country's first Center for Research and Therapy of Epidermolysis Bullosa. We know that $25,000 is pennies compared to what is needed, but it is still our hope that our government will become partners with us in this task and federal support for such Centers will be forthcoming.

In this respect we are extremely concerned and discouraged about the President's 1984 budget for NIH. As you know, the majority of research for skin diseases is funded through the Arthritis, Musculoskeletal and Skin Diseases cluster of the NIADDK. The $419.5 million appropriated for NIADDK is barely enough to sustain the existing research efforts of the Institute. Unless the NIADDK receives a substantial increase, it will be unable to support its current level of activity. Realistically speaking, what chances are there of "new" areas, like EB, being funded?

Mr. Chairman, I know the only real hope for my son and other youngsters who suffer from the various forms of EB will depend on advances in basic science. This can only be achieved through an expansion of NIH funding of skin biology and other programs. But I also know that the needs of these patients and their families must be addressed in a more immediate and creative fashion. Perhaps initially by establishing a series of referral centers that can deal with the formidable problems posed by this disease. Ultimately, however, I believe the real answers to EB require a multidisciplinary approach and inter-institute coordination on this disease and other disorders affecting the dermal-epidermal junction of the skin.

I would like to conclude my testimony by making two specific recommendations:

1. That Congress increase the NIADDK budget to $475 million to allow it to continue to fund its existing research programs.

2. That specific language be included in the final bill that directs the NIH, specifically the NIADDK, to strengthen and expand its research programs in EB and EB-related diseases.

The NIH has done an outstanding job in developing policies and programs that are fair and reasonable in many critical areas. They must now make a firm commitment and take positive action to develop programs that will address some of the key questions in this debilitating and often fatal group of diseases. The problems of EB must be attacked on several levels: 1) clinical care, 2) directed or applied science, and 3) skin biology, in general.

I do not think there is an alternative. As long as children continue to be born with EB, we must do everything we can to help them live useful and productive lives.

I thank you for giving us this opportunity to present our views. I hope this Committee will look favorably on our recommendations this year as they have in the past.

Thank you.

FACTS ABOUT EPIDERMOLYSIS BULLOSA
"An Orphan Disease"

1. Epidermolysis Bullosa (EB) is a complex group of inherited multi-organ system disorders which causes blistering and destruction of the skin and mucous membranes in both the gastrointestinal and respiratory tracts. In many cases, EB resembles a severe burn.

2. EB may cause a lifetime of pain, scarring, crippling, deformity, esophageal stenosis that can lead to malnutrition, dehydration, impaired growth, diminished muscle mass and tone, starvation, corneal erosions, dental difficulties and squamos cell carcinoma. In the severe forms premature death is inevitable.

3. 20,000 - 25,000 young Americans may suffer from EB. Another 40,000 - 50,000 may be carriers. There is no test to determine who the carriers are. Parents at risk are seldom referred for genetic counselling.

4. Deformities, disfigurement and social stigma cause many patients to lead seclusive lives. High divorce rate and broken family relationships are common and widespread.

5. Exhorbitant medical costs. Usually not covered under insurance plan, SSI or medicaid programs. Many states do not recognize EB under existing Crippled Childrens or Developmental Disability programs.

6. High rate of institutionalization of young children.

7. Information on EB scarce; seldom distributed.

8. Families run all over the world searching for unproven, untested miracles and cures.

9. Little treatment. No known cure. Limited research funds available or allocated to study the causes, treatment and prevention of EB and EB-related diseases.

February 22, 1983

Senator Jennings Randolph
U. S. Senate
Washington, D.C. 20510

Dear Senator Randolph:

My wife and I have recently experienced a tragedy in our lives. We would like to share our story with you in hopes of helping someone in the future. On November 27, 1982 our child was born with epidermolysis bullosa. He died four days later. I have enclosed a photograph so that you can truly appreciate the dreadful nature of this malady. The photograph does not need to be returned.

Our lives were severely impacted by this tragedy. E.B. is a genetically transmitted disease of varying severity. 25% to 50% of children of carriers will be affected with the disease. At present there is no way to detect the carrier state or to accurately diagnose the disease in the prenatal state. We cannot risk having other children because of these overwhelming odds, and because of the severity of the disease.

Legislative support for research is desperately needed. Research to determine the carrier state, establish the diagnosis prenatally,and to seek a treatment and cure for the disease deserves government support at all levels.

DEBRA (Dystrophic Epidermolysis Bullosa Research Association) is currently the organization seeking to find answers to this devastating disease. In addition to its research orientation, DEBRA provides bewildered and overwhelmed parents with information and moral support. It was a great relief to us to find this organization in existence at the time of our tragedy.

E.B. is now classified as a skin disorder, and should be classified as a genetic disease so that it can be funded with diseases such as cystic fibrosis and sickle cell anemia. Your attention to these matters is appreciated. Hopefully, legislation to classify E.B. as a genetic disease and legislation to provide research funds will be forthcoming. My wife and I would appreciate hearing about any legislation which is pending or forthcoming about epidermolysis bullosa.

Sincerely yo

Marla Van Dyke

Paul Van Dyke, M.D. and Marla Van Dyke

LETTER FROM STEPHEN BLANK, PRESIDENT, NATIONAL FOUNDATION FOR ILEITIS AND COLITIS, INC.

April 19, 1983

Senator Lowell Weicker, Jr., Chairman
Labor-HHS-Education Appropriations
Subcommittee
SD-186 Dirksen Senate Office Building
Washington D.C. 20510

Dear Chairman Weicker:

The NFIC with a membership of over 20,000 persons with inflammatory bowel disease (ileitis, Crohn's disease, ulcerative colitis) and their families and friends, is greatly concerned about the status of digestive disease research programs of the NIADDK and other NIH institutes.

NFIC's primary program is the support of IBD research. Currently, 26 research grants and one special research workshop at a total cost of $752,000 are being funded by NFIC. It is essential however, that the NIH research program in IBD remain our principal partner in advancing the knowledge and understanding of the cause, treatment and cure of IBD.

It is our belief that a core center research program in IBD would help considerably in hastening the day when these chronic diseases no longer destroy the lives of 200,000 youngsters and 1 3/4 million adults. These chronic diseases cause an estimated $645 million in economic loss annually to the nation.

We urge you to consider the need and the relative cost involved in providing the NIADDK with sufficient new funds to properly underwrite a Centers program. The arthritis and diabetes center programs have proven to be a highly successful mechanism within which important basic and clinical research is pursued.

We know the digestive disease organized professional community believes in and supports the creation of a Digestive Disease Centers program. However, we as patients are equally eager to have this program enlarged and enhanced.

It would be appreciated if you would please include this letter and the attachments in the Hearing Record of your public witness testimony on this important matter.

Sincerely,

Stephen Blank

Stephen Blank
President

FACTS ABOUT

THE NATIONAL FOUNDATION FOR ILEITIS & COLITIS

FOUNDED:

- 1967 as a national voluntary, non-profit health agency by:
  - Irwin M. Rosenthal, past President and Chairman

- William D. Modell, past President and Chairman
- Henry D. Janowitz, M.D., past Chairman, National Scientific Advisory Committee

PURPOSE:

- To fund research into the cause and ultimate cure of ileitis (Crohn's disease) and ulcerative colitis, inflammatory bowel diseases (IBD) affecting an estimated 2,000,000 Americans, for which the cause and cure remain unknown.
- Through public education programs, to inform patients, physicians and the general public of early warning symptoms, provide increased awareness of the diseases, de-mythologize ileitis and colitis, and better equip patients and their families to cope with the everyday effects of the diseases.

MEMBERSHIP:

- 15,000 members nationwide, comprised of lay volunteers and physicians (including internists, gastroenterologists, family practitioners, pediatricians and surgeons).

ORGANIZATION:

- National Headquarters
  295 Madison Avenue
  Suite 519
  New York, New York 10017
- 35 chapters in 18 states: California, Connecticut, Florida, Illinois, Louisiana, Massachusetts, Michigan, Minnesota, Missouri, New Jersey, New York, North Carolina, Ohio, Pennsylvania, Rhode Island, Texas, Virginia, Washington.

RESEARCH:

- Since founding, NFIC has awarded in excess of $6,000,000 to scientists and physicians engaged in IBD research in major medical centers and universities throughout the United States, Europe, Israel and Australia.
- Prior to establishment of the NFIC, research in IBD was virtually non-existent.
- Grant awards are made by determination of the Grants Review Committee of the National Scientific Advisory Committee, a body comprised of leading scientists and physicians from across the United States.

- The Research Training Awards Program, begun in 1977, supports and encourages young gastroenterologists to engage in IBD research. Since established, it has made awards in excess of $650,000.

FUNDING:

- NFIC is solely supported through tax-deductible private contributions.
- NFIC receives no federal or state funding.
- At the close of the most current fiscal year, September 30, 1981, NFIC had raised $1,380,500 and spent it as follows:
  - Programs: 73% of total expenditures
    - Research: 48.1% of total expenditures
    - Public and Professional Education: 24.9% of total expenditures
  - Supporting Services: 27% of total expenditures
    - Fundraising: 16.1% of total expenditures
    - Management: 10.9% of total expenditures

PUBLIC AND PROFESSIONAL EDUCATION PROGRAMS:

- Patient and public education efforts are targetted to raise general awareness of ileitis and colitis, what the diseases are and how patients and their families can cope with them. Program efforts include:
  - Public educational meetings and seminars on topics ranging from symptoms and diagnosis to treatment and formation of self-help groups.
  - Chapter newsletters, a quarterly national newsletter, and educational brochures and pamphlets.
- Professional education efforts seek to keep the medical community abreast of the most recent research, detection and treatment findings through NFIC-sponsored conferences, research reports and articles published in professional journals.

STATEMENT OF JOHN HENDERSON, SENIOR VICE PRESIDENT, TEXTRON, INC., ON BEHALF OF FRIENDS OF EYE RESEARCH

Senator ANDREWS. Our next witness is Dr. John Henderson, the senior vice president of Textron, Inc., speaking for the Friends of Eye Research.

Mr. Henderson, it's good to have you here.

Mr. HENDERSON. Senator, thank you.

Senator ANDREWS. Let me assure you that your entire prepared statement will appear in the record, and you may proceed to summarize it in any way you wish.

Mr. HENDERSON. I shall do so.

Mr. Chairman, I'm John Henderson. I'm senior vice president of Textron, a company in Providence, R.I., here on behalf of Friends of Eye Research.

You do have my statement.

Senator ANDREWS. Yes, I do.

Mr. HENDERSON. I am blind myself from an irremedial degenerative eye disease and, therefore, perhaps can speak a bit for the 11.5 million people in this country who have some kind of uncorrectable, serious eye ailment. All that stuff is rather sad, but there is always a silver cloud, and since I can't see the testimony, you are protected from having me read it. [Laughter.]

Senator ANDREWS. Well, earlier on before you came, I told the story by Mark Twain about the preacher that went on too long, and they began taking less and less from the collection plate.

Mr. HENDERSON. I'm sorry to have missed it, but I'll remember. [Laughter.]

The Friends of Eye Research are advocating a budget for the National Eye Institute for fiscal year 1984 of $191 million. That would provide for a rapid increase, an accelerated increase in the rate of eye research which we think is critical in this country.

The budget proposed by the President is about $143 million, which is just about the same budget as the prior year, in each case much too low we believe to deal with the kind of effective eye research which can be done now, which I, as a businessman, would say is highly effective cost research—cost effective, because the more you can do to eliminate blindness, the more you cut down on medical costs and make people a whole lot more productive in society.

There are three reasons why we recommend this specific budget.

First, it is the product of the new 5-year study by the National Advisory Eye Council, the distinguished group of doctors and researchers throughout the country who have carefully analyzed the work that can be done over the next 5 years, that can be done effectively.

Second, a great deal of work needs to be done in the area of low-vision blindness. Of the people who are legally blind, 90 percent have some low or residual vision, and a great deal can be done to make their lives more effective and perhaps to correct or improve their vision to some extent. And this is an area in which research has been not nearly as abundant or effective as it should have been.

Third, there is one specific area of which there's a great deal of optimism and that is research in connection with a series of drugs which may cure or very much retard the onset of the kind of cataracts referred to I think as sugar cataracts.

There are now approximately half a million—it's unbelievable, really—almost half a million cataract operations a year in this country. Obviously, if you can cut down on cataracts you greatly decrease the cost of medical care. I'm plainly here for Friends of Eye Research, not for the medical fraternity.

And in addition, it's very much a humane undertaking.

The proposition is a 3-year study in connection with a pharmaceutical house of this series of drugs. A great deal of the cost of the study will be taken on by the pharmaceutical house and the balance under this budget.

Finally, I would like to emphasize that the records indicate that the National Eye Institute is particularly effective in its use of funds. The cost per research grant is lower I believe than any other area of NIH. They get very much value for their money, and 94 percent of the funds which are allocated by NIH go to investigator grants, independent investigator grants which maintain the level of high quality eye research throughout the country.

I am advised that if we stick with this $143 million budget, we will retard and really impair, for a period of as much as a decade, the development of effective eye research in the country.

Thank you, Mr. Chairman.

PREPARED STATEMENT

Senator ANDREWS. Thank you very much for an excellent statement. It's good to have you here.

Mr. HENDERSON. It's good to see you, Senator.

[The statement follows:]

STATEMENT OF JOHN B. HENDERSON

Mr. Chairman, I am John B. Henderson, Senior Vice President of the Textron Corporation, headquartered in Providence, Rhode Island. I am here to speak on behalf of Friends of Eye Research, a nationwide public education and information organization that I understand is no stranger to this Subcommittee. As a person who has lost most of his vision becuase of an as-yet irreversible eye disease, I hope in some small measure to represent 11.5 million people in our nation who are victims of major, and still uncorrectable, eye problems.

Their ranks could double over the next half century unless Congress makes possible the rapid acceleration of progress against blinding vision problems. To accomplish that goal this year means going well beyond the Administration's meager recommendation for the National Eye Institute (NEI) in a budget appropriation for fiscal year 1984. It means further recognition by this Subcommittee, and by your colleagues in the Senate, that it is vastly more humane -- and considerably less expensive -- to keep people from going blind than it is to maintain these people once they have lost vision.

Friends of Eye Research shares a concern already expressed by members of this Subcommittee; namely, that a budget of $143.275 million as recommended by the President could set eye research back by as much as a decade. It would permit funding of only 1 out of 3 new and competing grants generated by the highly talented researchers that have been gathered together through the years in the productive clinics and laboratories throughout the country. Such a critical reduction in the funding of new grants would effectively break the backbone of eye research as we know it today in the United States. In addition, support of on-going grants would have to be cut, as would the critical reimbursement of indirect costs needed to carry out these projects. In short, the newly-revised 5-year plan for growth of eye research in our nation is seriously threatened by what the Administration is recommending. Indeed, the very fabric of the eye research effort is challenged by this 1.2% proposed increase for NEI.

There is a viable budget alternative. But before I discuss it, I believe the members of this Subcommittee first need to know why NEI seems to be able to fund grants at a rate that is higher than the rate of other institutes at NIH. For several years, NEI has been able to fund nearly one-half of the approved new and competing grants. There are two reasons for this outstanding performance: First, the average cost of a project grant at NEI is lower than for most other institutes, reflecting what I believe is the careful scrutiny by study section, Council, and staff of proposed budgets. This makes limited funds stretch further. Secondly, the NEI commits a larger percentage of its extramural budget (94%) to investigator-initiated grants than any other institute. NEI has almost no center grants or expensive program/project grants. This reflects the commitment to investigator-initiated research grants that NEI holds so strongly. Thus, it might be a better comparison of funding rates to measure the extent of funding of full-time-equivalent scientists (though such a measure would be difficult to get).

Returning to the question of increased NEI funding for fiscal year 1984; Friends of Eye Research and its distinguished Scientific Advisory Committee feel that this year can be a year of unparalleled advances in eye research and treatment. Here are just a few of the reasons why this could be so:

1. The scientists in the eye research community, under the coordination of the National Advisory Eye Council, have just completed a revised five-year plan for eye research in our nation. This new plan recognizes progress made during the past five years, identifies those areas that could not be addressed during that earlier period because of insufficient funds, and details once again the opportunities for successful research against blinding eye diseases. With this report, the eye research community renews its commitment to review, evaluate, and project its efforts on behalf of those threatened with loss of vision.

2. Within this plan -- for the first time -- is a major commitment to research addressing needs of people with partial

sight. This is noteworthy because most of the legally blind people in this country have some useful, residual vision. Although not totally without sight, this low vision population has been underserved by the research community. There now is strong reason to believe that through NEI-sponsored research, much can be done to help this population, which includes 90% of all those classified as legally blind.

3. A program which is very exciting to me as a layman is just about to get under way. It involves clinical trials for a new drug that combats some types of cataracts. Preliminary studies strongly indicate that this new series of drugs will either prevent so-called "sugar cataracts" from forming all together, or retard their growth for up to a decade. With cataract surgery in this country rapidly approaching half a million cases each year, think what such cataract prevention would mean to the victims, and to the medical economics of the situation as well.

For this study, NEI will be working closely with a major pharmaceutical firm, collaborating in a nationwide, three-year trial. Many research centers will be involved in this project. But in keeping with the new imperatives for private sector involvement in matters of public concern, the largest part of support for these trials -- more than $7 million --is being supplied by the pharmaceutical company. Thus, considerable tax money will be saved.

Even bigger savings to the country as a whole will be realized if results of these trials are as positive as the researchers hope they will be. The cost for treatment of these cataract victims will be substantially lower if these new drugs are successful. We could not have reached this point if Congress had not made possible the funding of research on anti-cataract drugs in the past.

These are some of the cogent reasons why Friends of Eye Research endorses a budget of $191 million for the National Eye Institute in fiscal 1984. This amount will maintain and expand the research effort that has already saved many times the program cost through advances in treatment made possible through prior research. The $191 million budget will permit scientists to take fuller advantage of research opportunities outlined in the revised five-year plan.

As a citizens' organization Friends of Eye Research must point out the urgent need for that amount of funding. We recognize that the National Advisory Eye Council has recommended the same amount, with the hope that Congress will take advantage of these opportunities for winning the war against blindness sooner rather than later.

Gentlemen, there are millions of your fellow citizens waiting to be helped. Their only hope for new treatment breakthroughs lies in research. This hope can be fostered only through adequate financial support of the research. Friends of Eye Research joins with others in urging passage of a $191 million budget for NEI for FY1984.

CITIZENS' BUDGET for the NATIONAL EYE INSTITUTE for FY 1984

(Figures in millions)

	FY 1983 Estimate	FY 1984 President's Budget	FY 1984 Citizens' Budget
BY PROGRAM			
Retinal and Choroidal Diseases	$52.2	$54.4	$66.3
Corneal Diseases	18.4	18.4	26.6
Cataract	11.1	11.2	17.3
Glaucoma	12.7	12.7	17.4
Strabismus, Amblyopia, and Visual Processing	26.8	26.9	41.9
Subtotal, Extramural Research	121.2	121.6	169.9
Intramural Laboratory and Clinical Research, Biometry, Epidemiology, and Field Studies	14.6	15.6	15.6
Research Management and Program Services	5.8	6.1	6.1
Subtotal, Intramural Activities	20.4	21.7	21.7
TOTAL	141.6	143.3	191.2
BY MECHANISMS			
Research Grants	$106.8	$106.5	$139.5
Core Grants	4.7	4.9	6.5
Construction, Renovation, and Biotechnology Resources	-	-	10.0
Individual Training	1.3	1.4	3.0
Institutional Training	2.6	2.3	3.0
Subtotal, Grants	115.4	115.1	162.0
Intramural Laboratory and Clinical Research	13.9	14.9	14.9
Research and Development Contracts	5.8	6.5	7.5
Biometry, Epidemiology, & Field Study	.7	.7	.7
Research Management and Program Services	5.8	6.1	6.1
Subtotal, Direct Operations	26.2	28.2	29.2
TOTAL	141.6	143.3	191.2

STATEMENT OF SYLVIA N. RACHLIN, EXECUTIVE VICE PRESIDENT, MYOPIA INTERNATIONAL RESEARCH FOUNDATION, INC.

Senator ANDREWS. Our next witness is Sylvia Rachlin, who is the executive vice president of the Myopia International Research Foundation, Inc.

Mrs. RACHLIN. Thank you, Mr. Chairman.

Senator ANDREWS. It's good to have you here.

Mrs. RACHLIN. You have my statement.

Senator ANDREWS. We do, and it will be included in full in the record, and you can summarize it or highlight it or make additional comments in whatever way you choose.

Mrs. RACHLIN. Thank you so much, Senator. I'll just need about a minute.

Last fall, about 16,000 eye doctors from mostly all nations of the world gathered in San Francisco, and long lines of these doctors stood waiting to see the exhibits of the National Eye Institute. We were so proud. And I wish you could have heard the comments of respect and admiration.

The experts have already mentioned to you, I believe, the kind of eye research that is desperately needed now, and eye patients everywhere can testify as to the urgency.

The prevention of blindness and rehabilitation of the visually handicapped so that they may be employed certainly reduces the tax burden. The greater the investment, the greater the return.

We appeal to you, we, the public, beg of you: please approve the $191 million budget, which is the minimum amount for the National Eye Institute and, Mr. Chairman, I believe that in not too many years you will see some happy surprises.

Thank you.

Senator ANDREWS. Thank you very much for an excellent statement. Your statement will be placed in the record at this point, along with other statements submitted for the record on appropriations for the National Eye Institute.

[The statements follow:]

STATEMENT OF SYLVIA N. RACHLIN

Americans spend over $5 billion annually on eye care. In addition, eye disorders account for suffering in individuals and their familes that is beyond all statistical measurement.

The Myopia International Research Foundation urges increased dedication to all research that would promote early detection, treatment, and prevention of eye disorders. Healthy eyes in childhood offer greater promise for a happy and productive life.

The Myopia International Research Foundation is convinced that research into the causes, treatment, and prevention of myopia could revolutionize the entire practice of eye care and promote the prevention of blindness. Moreover, results of research reduce the tax burden and restore the handicapped to tax rolls. The greater the investment, the greater the return, even in these times.

We, therefore, appeal to this honorable committee that it give its generous support to the requests of the National Eye Institute to make possible adequate grants for research. The returns will prove most beneficial to our national health and economy.

PERTINENT FACTS

The Myopia International Research Foundation, Inc. launched the first comprehensive, interdisciplinary research program in the United States into the causes, treatment, and prevention of nearsightedness.

Our immediate goal is to save the eyesight of more than 1 million American children (besides millions around the world) who are doomed to blindness because of progressive, pathological myopia for which there is no known cure. This, we are doing with the cooperation of doctors in the United States and elsewhere throughout the world.

The Myopia International Research Foundation sponsored the First International Conference on Myopia in 1964.

Since 1965 the Myopia International Research Foundation has appeared before Appropriations subcommittees of the U.S. Senate and House of Representatives appealing for increased support of eye research through the National Eye Institute. Each year, this foundation has been one of the public witnesses invited by these committees to present testimony on needed eye research for the Nation under the National Eye Institute.

The Myopia International Research Foundation has been invited to exhibit at conventions of the American Academy of Ophthalmology. An increasing number of ophthalmologists has become interested in our program.

The Myopia International Research Foundation has exhibited at International Congresses of Ophthalmology since 1966, most recently at the 1982 International Congress in San Francisco. These presentations have been enthusiastically received by eminent doctors from around the world.

The Voice of America has broadcast details of our program on two occasions.

The Myopia International Research Foundation is idealistic in its operation. No money whatsoever is spent on administrative salaries or professional fundraisers.

The Myopia International Research Foundation has launched the myopia international research network to promote worldwide coordinated scientific research on myopia by doctors and interested patients.

LETTER FROM ROBERT D. REINECKE, M.D., SECRETARY, AMERICAN ACADEMY OF OPHTHALMOLOGY

APRIL 29, 1983.

The HON. LOWELL P. WEICKER, JR.,
Chairman, U.S. Senate, Subcommittee on Labor, Health and Human Services, Washington, D.C.

DEAR SENATOR WEICKER: The American Academy of Ophthalmology is pleased to support the citizens budget of the NIH, National Advisory Eye Council.

The academy joins other organizations including Research to Prevent Blindness and Friends of Eye Research in support of a request of $191 million for NEI in fiscal year 1984.

I would like to request that this letter and the attached position paper be included for the record.

Thank you for your consideration.

Sincerely,

ROBERT D. REINECKE, M.D.,
Secretary.

POLICY

The American Academy of Ophthalmology supports adequate congressional appropriations to properly fund useful research and operational moneys for the National Eye Institute (NEI).

BACKGROUND

The National Eye Institute is the primary source of support for vision research. From its investigations into the normal and abnormal structure and function of the visual system, significant contributions to biomedical science have been made during the past decade. Of a work force of 12,000 at the National Institute of Health, NEI employs about 160 people, representing approximately 1 percent of the NIH budget. NEI funds approximately 80 percent of all vision research supported by the Federal Government and national private philanthropic organizations.

EVALUATION

The way in which NEI is managed is regarded as a model for other institutes at NIH. At NEI, planning is deemed an integral part of the organization. To assist the planning process and provide direction, the National Advisory Eye Council was established. The council is comprised of 12 individuals from basic and clinical vision research, eye care, and the public at large. The council advises the NEI Director and his staff on grant awards and program/policy development.

As part of NEI's planning process, a vision research national plan has been developed. More than 160 leading representatives of the vision research community developed this plan, relying on the council's report for guidance in the background, rationale, and principles of vision research program planning. Under the direction of Dr. Carl Kupfer, the process has been refined even further, and the finishing touches for the third national plan are being applied.

The council estimates that fiscal years 1984, 1985, and 1986 budgets of $191, $208, and $225 million respectively, are required to sustain the progress made with the treatments for diabetic retinopathy, uveitis, glaucoma, and other vision impairment diseases. This amount would support 1,349, 1,410, and 1,460 research projects for fiscal years 1984, 1985, and 1986 respectively. These sums still represent, however, a reduction from the 1,516 projects in the vision research plan funding recommended by the council in 1978. In response to budgetary constraints, NEI has planned cutbacks in areas such as basic psychophysics research. It is important that the Institute has been able to maintain its funding flexibility. To avoid mandatory commitments that would limit future options, NEI does not fund large program project grants or other umbrella grants.

SUMMARY

The NEI was appropriated $127 million in fiscal year 1982 and approximately $141 million in fiscal year 1983. The council's proposed NEI budget for fiscal year 1984 is $191 million. This budget is based on a sophisticated planning process that recognized the significant savings made possible by previous research expenditrues. For example, findings from the Institute's diabetic retionopathy study have prevented thousands from going blind, resulting in estimated savings of over $4 billion to the economy. Findings from recent research indicate that it may be possible to use drugs that will retard cataract formation enough to delay surgery 10 years. If this occurs, it may be possible to delay 180,000 cataract operations for 10 years, representing a $3 billion savings.

The American Academy of Ophthalmology urges Congress to recognize the achievements of the NEI, and to vote for an increase in the NEI budget for fiscal year 1984 to sustain vision research capabilities.

Approved by Governmental Relation Secretariat, April 30, 1982.
Approved by Board of Directors, June 26, 1982.
Revised May 1983.

STATEMENT OF HORACE D. GODFREY, PRESIDENT, GODFREY ASSOCIATES, INC., AND VICE PRESIDENT, FLORIDA SUGAR CANE LEAGUE

Senator ANDREWS. Our next witness is Mr. Horace Godfrey representing the Florida Sugar Cane League.

Mr. Godfrey.

Mr. GODFREY. Thank you, Mr. Chairman.

Senator ANDREWS. It's good to have you here.

Mr. GODFREY. I have made a few revisions in my original testimony that was submitted, and I would like to give you some revised copies.

Senator ANDREWS. Be assured that your total statement will appear in the record word-for-word. And you may summarize it in any way you wish.

Mr. GODFREY. Mr. Chairman, first I would like to thank you for the many, many long years of dedication to service to the public, and particularly in the areas that we're dealing with today.

I appear today not as a researcher or a specialist, as you well know, or a doctor, but I appear as a layman. Maybe you might consider me a researcher since I'm an avid reader, and I appear on behalf of the Florida Sugar Cane League instead of the American Sugar Cane League. I don't know how that got crossed up, but is the Florida Sugar Cane League.

My interest in the area of dental caries has been a long one, not simply because I'm associated with sugar but because of the so-called antisugar bias that I think seems to prevail in the minds of many of the general public and also in the minds of some government officials.

My interest was heightened a few years ago when my longtime personal dentist suddenly discovered that I was representing some sugar producers, and he was amazed and awed that I would be representing anybody that produced a product that was detrimental to an individual's health and that caused dental caries.

Well, I proceeded to ask him then how he became a nutritionist, and how he was so interested in dental caries, and where he got all of his information. And he told me that he'd never had any courses in nutrition, then he really started thinking and said: I guess I've just heard it all my life.

So I proceeded then to try to educate him on dental caries.

Over the last 10 years, as you well know, the National Institute of Dental Research has been pursuing efforts to reduce the incidence of dental caries. My purpose in appearing today I guess is twofold: I want to congratulate them, first, on the successes they have achieved; because it's amost unbelievable when you read about reductions as high as 35 percent in the incidence of dental caries. They indicate that the large scale use of fluoride in several mouthwashing programs, municipal water supplies and toothpaste, as well as new developments, have played an important role in this reduction of dental caries.

I also want to congratulate them on their efforts to bring to the attention of the American public that there are other causes for dental caries beside sugar consumption. Among scientists it is a well understood fact that any carbohydrates can cause dental caries, and that they do cause dental caries.

Furthermore, I think it is now understood among scientists, but not necessarily among the general public, that the natural sugars contained in fruits and vegetables are cariogenic, as are the starches in other natural and processed foods.

Recently you placed into the record an article by Dr. Moss, and I will not read that, I won't put it in the record: you put it in there; but I was impressed with it. And I'll just read the last part of it. He says:

> Bacteria in the mouth can't read labels. We need to switch the focus from what and how much carbohydrates we eat to how often, how frequently we eat them during the course of the day.

Since you put that in the record, I found another statement which echoes Dr. Moss' statement. This statement was made by two noted dental researchers 2 years ago in an article for a British dental journal. It's brief, so I'd like to read it.

In this article entitled "Dental Caries and Sugar Intake," the authors, Dr. Walker and Dr. Cleaton Jones, warn, and I quote:

> * * * of the beliefs which, when they are of longstanding become fixed rules of life and assume a presumptive right not to be questioned. Entrenched belief that sugar is an arch-villain in caries development lies in this category.

This was made by two noted dental researchers a long time ago.

Just recently, Dr. Carlos said in an article for the American Dental Association in February 1982, entitled "The Prevention of Dental Caries—Ten Years Later," this is a summary of what's been done:

> Of the research efforts to effectively intervene in the etiologic triad of dental caries, those directed at altering dietary factors have so far met with the least success.

Now, that brings me to the second point of why I appear today.

If they cannot modify the American diet, if they cannot find substitutes for natural sugars in fruits and vegetables, then why are we continuing the expenditure of funds for research in this area? Wouldn't it be a better expenditure of funds, and better use of the funds, if we would expand the knowledge that we now have, and that they now have, for the prevention of dental caries: expansion of the use of fluorides and other techniques, and not be searching for an alternate sweetener. If they found an alternate sweetener that was noncariogenic, how are they going to replace it in fresh fruits and vegetables? How are they going to replace the sweeteners in processed foods containing these natural fruits and vegetables that contain natural sugar?

So my suggestion is that the committee look at the expenditure of funds particularly in the area for developing new sweeteners. I seriously question myself whether this is a role of Government or not. They haven't found any alternate sweeteners in 10 years now. There's been about three found by private enterprise, and in each case there have been some problems with those. And what they have found do not possess the same bulking properties that sugar does, the same cooking properties that sugar has.

So wouldn't it be better, then, if these funds were redirected—it's not a large amount of money: wouldn't it be better if it was redirected to the known causes of preventing dental caries.

Senator Andrews. Well, Mr. Godfrey, early on in your oral statement, you said that the research that has been conducted with these Federal funds is, in your opinion, biased research. I glanced through your statement while you were summarizing it, and I don't see specific examples of that. Obviously, whatever research this subcommittee funds, and I speak as only one member of it, we want to make sure that it's nonbiased, otherwise you might just as well throw the research out the window.

Can you provide any specific examples——

Mr. GODFREY. I probably misstated the bias. I think there prevails throughout Government an antisugar bias. For example, sugar is blamed for everything. You've read it, I've read it. But there is no medical science to back it up.

Medical science backs up that sugar may be a contributor to the cause of dental caries, and no other health hazards whatsoever. The research that they have done, and the research that has been published in recent years, bears this out, that sugar is no more guilty of dental caries than other carbohydrates.

PREPARED STATEMENT

Senator ANDREWS. Thank you for a good statement, Mr. Godfrey. It's good to have you here.

Mr. GODFREY. Thank you.

[The statement follows:]

STATEMENT OF HORACE D. GODFREY

Mr. Chairman, my name is Horace D. Godfrey, and I appear today as representative of the Florida and Texas sugarcane growers and processors. For several years I have had a keen interest in the National Institute of Dental Research (NIDR) and the National Dental Caries Program. I do not profess to be a scientist, researcher, nutritionist or specialist in the health or dental field. A question may be asked, "Why then are you here as a witness?" I guess that the best way to answer this is to say that I have become an avid reader and researcher, if you may call it that, on all available data, published or unpublished, on sugar and health, and particularly on dental caries.

My interest in these areas was heightened a few years ago when my longtime personal dentist suddenly assumed the self-appointed role of nutritionist and dental scientist by openly condemning sugar to me as dangerous to my general health and as the cause of dental caries. In questioning my family dentist, I learned that he had no training in nutrition and that he possessed no proof that sugar was injurious to health or was the major cause of dental caries. I subsequently furnished him with a publication entitled "Sugar in the Diet of Man" by Dr. F. J. Stare, Department of Nutrition, Harvard School of Public Health. This publication contained a collection of articles by world renowned scientists presented at the World Review of Nutrition and Dietetics in 1975. Later I sent him research findings and articles published by the National Institute of Dental Research and other organizations and individuals. I have found that not only my dentist, but also a large percentage of the people with whom I have come in contact, hold incorrect opinions on this subject.

My purpose in appearing today is two-fold. First, I would like to congratulate the NIDR for the successes achieved in reducing the incidence of dental caries in America. From what I have read, NIDR reports reductions as high as 35%, and the NIDR specifically points out that this reduction in tooth decay was achieved without any overall reduction in the consumption of sugar by Americans. NIDR indicates that the large scale use of fluoride in school mouth-washing programs, municipal water supplies and toothpaste, as well as new developments such as implanted fluoride time-release capsules, have played an important role in this reduction of dental caries.

I want to congratulate NIDR also for its efforts to bring to the attention of the American public that there are other causes for dental caries besides sugar consumption. Among scientists, it is a well understood fact that any carbohydrate can cause dental caries and that they all do cause dental caries. Furthermore, I think it is now understood among scientists, but not necessarily among the general public, that the natural sugars contained in fruits and vegetables are cariogenic, as are the starches in other natural and processed foods.

Recently I read a news article quoting Dr. Stephen Moss, Chairman of the Department of Pedodontics at the New York University Dental Center who cautioned that simply reducing total sucrose intake would not prevent dental caries, a fact which the American Dental Association was reported as recognizing.

> Dr. Moss had this to say: "As sure as I know night follows day, I always believed that refined sweets and gooey candies were the forbidden foods for healthy teeth, but for the last few years, ongoing dental research has shown a new focus on the diet-cavity connection. The new scientific data, coming in from numerous research centers worldwide, is too consistent to keep on believing that sweets alone are what plays havoc on our teeth. Since starches are broken down to sugars before they leave the mouth,

> we now look at all carbohydrate foods--whether the ones with simple sugars such as raisins, candy, jellies, bananas, and honey, or the complex sugars (starches), specifically the cooked ones like breads, cereals and potatoes--as being potentially cariogenic. Dr. Moss explained: "Bacteria in the mouth can't read labels. We need to switch the focus from what and how much carbohydrate we eat to how often, how frequently we eat them during the course of the day."

This statement by Dr. Moss echoes a statement made by two noted dental researchers sometime ago in an article for a British Dental Journal. In this article: "Dental Caries and Sugar Intake," the authors, Dr. Walker and Dr. Cleaton Jones, warned "of the beliefs which, when they are of long standing become fixed rules of life and assume a presumptive right not to be questioned. Entrenched belief that sugar is an arch-villain in caries development lies in this category."

I also want to congratulate NIDR for reaching the conclusion as expressed by Dr. Carlos in an article for the American Dental Association in February 1982 entitled "The Prevention of Dental Caries - Ten Years Later" in which he says, "Of the research efforts to effectively intervene in the etiologic triad of dental caries, those directed at altering dietary factors have so far met with the least success. Given the proclivity of a large segment of the population, and especially of children, for sweet foods, it seems futile to strive for major changes in dietary habits, even though there is compelling evidence that a sharp reduction in the amount, or even in the frequency of sugars eaten would have a salutary impact on caries prevalence. Instead recent research has been directed to identifying and developing substances that might be added to sugars to decrease their cariogenicity, or that could serve as taste-competitive, noncariogenic sugar substitutes." This quote, along with other research data, leads me to my second purpose in appearing today.

If it is futile to attempt to change the American diet, the question is raised as to why the NIDR continues its costly efforts to modify the American diet. As a matter of food processing technology, it is unrealistic to expect that synthetic sweeteners can be substituted for natural sugars, particularly sucrose, in the vast majority of processed foods. Sugar is a bulking agent and preservative for which no synthetic substitution can be made, and its natural taste qualities have simply not been equalled by any chemical replacement. Beyond that, it is obvious that people will continue to eat unprocessed foods, such as fruits and vegetables, which contain plenty of natural sugars, as well as starch foods which also are cariogenic. All the synthetic sweeteners imaginable couldn't have any effect in unprocessed foods and starch foods, whose cariogenic effects would continue. Dr. Carlos makes a strong point, in my opinion, when he speaks of "substances that might be added to sugar to decrease their cariogenicity." It would appear that instead of searching for alternate sweeteners, the NIDR funds could be better utilized in an effort to find additives that might reduce the cariogenicity of processed carbohydrate foods as long as this does not, at the same time cause cancer, hypertension or other medical problems.

Much more could be said about the search for alternative sweeteners. I do not believe that during all the years of the NIDR's operation of its National Caries Program it has had any success in finding an alternate sweetener. Alternate sweeteners have been developed by private industry, but these have had only very limited application and success, particularly due to their lack of the vital processing properties of natural sugars and the concerns about cancer which they have raised.

If the NIDR is to continue spending funds to find alternate sweeteners, how long would it take for such sweeteners to be tested and proven safe? Would they be acceptable to the public?

Would they have the essential processing properties and taste characteristics of natural sugars?

Thus, the question arises, is this type of activity an appropriate responsibility of government or should it instead be a marketplace opportunity for private industry?

Mr. Chairman, Members, I have appeared here today not only to raise some questions, but also to request that you look into the use of funds by the NIDR and that you urge it to do as Dr. Carlos has indicated, that is to redirect its focus away from groping for alternate sweeteners and instead towards an increase in the amount of fluoride available, or its means of transmission, or in the education of the populace to better dental hygiene and the benefits of fluoride.

STATEMENT OF DR. JAMES KERRIGAN, CHAIRMAN, COUNCIL ON LEGISLATION, AMERICAN DENTAL ASSOCIATION

Senator ANDREWS. Our next witness is Dr. James Kerrigan, the chairman of the council on legislation of the American Dental Association.

Dr. Kerrigan.

Dr. KERRIGAN. Good morning, Senator.

Senator ANDREWS. It's good to have you here.

Dr. KERRIGAN. Thank you.

Mr. Chairman and members of the Subcommittee: My name is Dr. James P. Kerrigan. In addition to maintaining a private practice in Washington, D.C., I'm presently serving as chairman of the council on legislation for the American Dental Association. I am appearing today on behalf of the American Dental Association and the American Association of Dental Schools.

Because of time constraints, I will keep my remarks very brief.

Senator ANDREWS. Be assured that your prepared statement will appear in full.

Dr. KERRIGAN. Thank you very much. And we'll submit a more comprehensive statement for the record.

Mr. Chairman, I'm sure you and the members of the subcommittee will agree that the cornerstone of good public health policy should be prevention. In dentistry we are particularly proud of our profession's record of focusing patients' attention on good dental health through prevention. However, we do not believe that the administration's budget recommendations provide adequate support for preventive approaches in dental care.

For example, the President is requesting a 2.3-percent increase in the funding for the National Institute of Dental Research. This represents only 75 percent of the sum provided to NIDR in the fiscal year 1973 when measured in constant dollars.

The American Dental Association and the American Association of Dental Schools recommend a fiscal year 1984 appropriation of $94 million for NIDR. We believe that this sum is justified because of certain high-priority areas which, in our opinion, cannot be adequately addressed within the administration's 1984 budget. These include the epidemiology of oral diseases and conditions; behavioral approaches to the prevention of oral diseases; expanded clinical trials, and the establishment of clinical research and training centers.

We also believe in continued support for health professional students and for programs to provide graduate training in primary care. These we feel are crucial.

Student assistance is, of course, vital if the profession is to remain accessible to the very best students, regardless of their economic status. The general practice residency program, in addition to training primary health care providers, also delivers direct care to the disabled and other patients requiring special treatment.

For the above reasons we recommend that $6 million be appropriated for the health profession student loans, and that $2 million be provided for dental practice residencies.

In addition, we oppose any increase in the guaranteed student loan origination fees.

Finally, we'd like to remind the subcommittee of the single most cost effective and beneficial dental health measure available to the general public, the fluoridation of community water supplies.

Recently, Surgeon General Koop, like every other Surgeon General over the past 30 years, reiterated support for community water fluoridation; yet the President's budget would eliminate all technical assistance funds for this important program. We ask the subcommittee to restore the $1.5 million for the dental disease prevention activity in the Centers for Disease Control.

Mr. Chairman, this completes my formal remarks. Thank you for the opportunity of appearing before you and expressing our concerns.

If you have any questions, I would be happy to answer them.

PREPARED STATEMENT

Senator ANDREWS. Thank you very much, Doctor, for the contribution you've made to our hearing today.

Dr. KERRIGAN. Thank you.

Senator ANDREWS. It has been good to have you here and to hear from you.

[The statement follows:]

STATEMENT OF DR. JAMES KERRIGAN

My name is Dr. James Kerrigan. In addition to maintaining a private practice in Washington, D.C., I am presently serving as Chairman of the Council on Legislation of the American Dental Association. I am appearing today on behalf of the American Dental Association and the American Association of Dental Schools. This morning I would like to highlight three major areas of concern to our Associations and, with the permission of the Subcommittee, submit a more detailed statement for the record.

Dental Research

Mr. Chairman, our Associations recommend a fiscal year 1984 appropriation of $94 million for the National Institute of Dental Research. Although this proposed level of funding is significantly above the $80.6 million requested by the Administration, we believe a justification for such an amount can be demonstrated by the following comparative statistics. In fiscal 1973, the dental research institute received an appropriation of approximately $47 million. Using that year as a base line, we find that the President's 1984 budget request for NIDR actually represents only 75 percent of the sum provided in 1973 when measured in constant dollars. This is the lowest percentage of all of the research institutes which, on the average, are currently funded at a level slightly in excess of the 1973 constant dollar appropriation.

The importance of increased support for NIDR is underscored by the additional fact that more than 80 percent of the dental research conducted in this country is financed by the dental institute. As we have noted in previous testimony, NIDR does not enjoy the complementary efforts of philanthropic and industrial sponsored research which is found among other disciplines.

The American Dental Association and the American Association of Dental Schools have identified certain high priority areas which in our opinion cannot be adequately addressed within the Administration's 1984 budget request: the epidemiology of oral diseases and conditions, behavioral approaches to the prevention of oral diseases, expanded clinical trials, and the establishment of clinical research and training centers.

Epidemiologic data on a number of oral diseases and conditions are critically needed as a basis for determining the magnitude of dental problems as well as for research planning purposes. For example, the 1979-80 National Dental Caries Prevalence Survey indicated a marked decrease in caries prevalence among children 5-17 years of age. However, a smaller proportion of the decrease in caries prevalence apparently has been experienced by older children. It is essential that a follow-up survey be conducted to observe disease patterns in these young adults as well as in older age groups.

The extent of periodontal diseases in our population has not been ascertained with any degree of accuracy. As a result of the increase in older segments of the population and the longer retention of teeth because of wide-spread use of caries-preventive measures, diseases of the supporting tissues are growing in importance. In addition, there are emerging oral diseases and conditions that need to be assessed for the first time on a national level. Dental caries of the tooth roots is a case in point. As more teeth are retained into old age, root surface caries is expected to become an increasingly serious public health problem.

There is also a critical need to determine patient motivational factors that influence the delivery of dental care. A more coordinated effort would facilitate the transfer of behavioral science knowledge to the practice of dentistry. Opportunities now exist to pursue behavioral research that would expedite the prevention of oral diseases and conditions, and to predict more accurately which individuals and groups will be responsible to particular behavioral interventions.

The most prevalent oral diseases (caries and periodontal diseases) are strongly influenced by factors such as flouride use, diet and personal oral hygiene practices. An improved understanding of how health-promoting behaviors can be established and consistently maintained would contribute greatly to the public's oral health and to reducing the economic, physical and social burdens imposed by oral diseases.

The accomplishments of basic science research have provided the underpinning for major advances in applied clinical research, especially as it relates to caries and periodontal diseases. However, funding for clinical trials, and clinical research and training is very limited. As a result, the final step in technology transfer from the research scientist to the clinician is severely hampered. For example, the range and scope of research activities directed towards the prevention of periodontal diseases has great potential for a breakthrough in the near future. Mechanical plaque removal remains the most common approach to prevention. In the 1960's it was demonstrated that home care, combined with professional care, greatly reduced periodontal diseases. The development of a cost-effective program for the public may be realized through clinical trials of school and work-based preventive programs. Clinical studies of agents that inhibit bacterial growth on the teeth and periodontal tissues are also ripe for implementation.

In conclusion, we believe that the need for data from clinical studies is so great that immediate steps must be taken to carry out the necessary research and training. A bottleneck exists in the transfer of technology from the laboratory to the clinic. As a result, the payback from the research dollars already expended is being unnecessarily delayed.

Dental Disease Prevention

There would appear to be a paradox in the position of the Administration with regard to the prevention of dental disease.

Earlier this year, Surgeon General C. Everett Koop followed the precedent of every Surgeon General since President Eisenhower by endorsing the flouridation of community water supplies. In his statement, Dr. Koop acknowledged that "Years of research and community demonstrations have shown that the flouridation of drinking water supplies is the most effective and least costly public health measure available to prevent tooth decay. Between half and two-thirds of the dental decay that children would have if unprotected is prevented if they drink flouridated water from birth," he said.

Unfortunately, this apparent commitment to dental disease prevention is largely absent from the Administration's proposed spending levels for fiscal 1984. Once again, no funds are requested for the dental disease prevention/flouridation activity at the Centers for Disease Control. This important program serves as (1) a national focus for promoting oral health through prevention and (2) as a source of technical assistance to states and local communities with flouride-deficient water supplies. Last year Congress restored support for this activity. We urge a similar action in the 1984 budget with an appropriation of $1.5 million.

Student Financial Assistance

There is a strong need for continued funding of student aid programs to ensure that a dental career will remain accessible to students from all economic backgrounds. Our Associations urge the Committee to leave intact the Guaranteed Student Loan program by rejecting the Administration's plan to assess graduate students an additional 5 percent loan origination fee. We also ask that you support the National Direct Student Loan program at the current level of $193 million and increase funding for the College Work Study program to the Administration's recommended level of $850 million.

The President's 1984 Budget proposes to eliminate funding for dental General Practice Residencies and for the Health Professions Student

Loan program. Let me briefly outline our reasons for recommending that minimal funding be restored to these programs.

Dental General Practice Residency programs provide advanced training for the treatment of handicapped and other patients requiring specialized or complex care. Demand for this training continues to be extremely high; last year 2,000 dentists applied for a general practice residency. However, only 942 could be accommodated. Past Federal support has been vital to the establishment and initial maintenance of these residency positions. A modest investment this year will allow for the creation of new residency positions which generally become self-supporting within three years. Accordingly, we recommend an appropriation of $2 million in FY 1984.

Health Professions Student Loans are an essential source of moderate interest (9%) loan money for dental and other health professional students. Recipients must have demonstrated financial need and many schools reserve these loans for those with the most severe financial situations. Continued federal capital contributions are needed to establish adequate amounts for a workable revolving account at each institution. This is particularly important for newer dental schools which require additional funds to develop a self-sufficient system. We ask that $6 million be appropriated for this program.

Recently, much attention was drawn to the problem of delinquent collection of these loans. Mr. Chairman, I am pleased to report that the nation's dental schools have made correction of this problem a top priority. During the first six months of this effort we have achieved a 34 percent reduction in the average delinquency rate. I am confident the Committee shares our view that this action represents a positive response to the concerns that have been expressed by Members of Congress.

STATEMENT OF DR. JAMES E. MULVIHILL, AMERICAN ASSOCIATION FOR DENTAL RESEARCH

Senator ANDREWS. Our next witness will be Dr. James Mulvihill, who is the vice president for health affairs and executive director of the University of Connecticut Health Center.

Doctor, Senator Weicker, our chairman, asked me to tell you he regrets he couldn't be here to hear your testimony, but he's most interested in your work, and will have an opportunity to review your testimony.

Dr. MULVIHILL. Thank you, Senator.

I am Dr. James Mulvihill, vice president for health affairs of the University of Connecticut Health Center, and am here appearing to make a statement on behalf of the National Institute for Dental Research. We have formally submitted a statement to you. I'd just like to make a very few comments.

The National Institute for Dental Research is one of the two or three oldest of the institutes of the NIH. It is also the smallest. It is our belief that perhaps in the last decade this institute has been overlooked both in terms of the contributions it has made and in terms of the funding.

In terms of its contributions to understanding and preventing dental disease, we have, as you heard from an earlier speaker, gained a reduction of at least 35, and, in many areas of the country now, a 50-percent reduction in dental caries through the use of fluoride and other preventive measures. The cost of the use of fluoride is 25 cents per person per year.

And the previous speaker also commented on the very small amount of money being asked to be restored to the President's budget, about $1,300,000, to insure the ability to continue doing this.

This has resulted in a savings of over $2 billion a year to the American public in direct out-of-pocket expenses just for the filling of dental caries, not for the sequellae that come on in later life when you need bridges and dentures, et cetera, just for fillings, $2 billion a year. And I think the million dollar investment in that area has gotten a very good yield.

The National Institute for Dental Research and the dental schools that do the research funded by it are on the threshold of understanding one of the other most common diseases of mankind, which is gum disease, periodontal disease, pyorrhea, as known to many other people. Ninety percent of teeth lost in people over age 35 in this country is from periodontal disease. It's a microbial disease caused by bacteria working on certain substances left in the mouth, carbohydrates and others, and it is one that we don't know the cure for yet; we don't understand all the immunology of it.

But dentals schools and the National Institute for Dental Research, through the funding received from you, are on the threshold of developing some very important preventive measures, including fluids which you just have to rinse your mouth with once a day to completely control the substances and eliminate them, that cause periodontal disease.

Dental diseases are the most common diseases of mankind: there's probably not anybody in the room who doesn't have some. There has been an increase as the population increases with aging, however: we do see an increase in periodontal disease. And the major thrust of the Dental Research Institute now is to understand the causes, and develop and refine the preventive measures.

Dental disease is also a big problem, as Senator Weicker knows, in the handicapped, not only aged people with reduced motor skills but also in other elements of the physically and mentally handicapped who cannot brush their teeth. Some of the things being worked out at the Dental Research Institute now will enable such individuals just to rinse their mouths once a day with these fluids that would effectively eliminate the causes of a lot of periodontal disease in this country.

The Dental Research Institute, therefore, is on the threshold of a lot of important breakthroughs. We are recommending that it be fully funded at $94 million, rather than the administration's level of approximately $80 million. We think that that is an important investment in terms of prevention, cost effectiveness that will benefit all the people of the United States in the years to come.

PREPARED STATEMENTS

Senator ANDREWS. Thank you very much, Doctor, for an excellent statement. Your statement will be placed in the record at this point, along with other statements submitted for the record on appropriations for the National Institute of Dental Research.

[The statements follow:]

Statement of Dr. James E. Mulvihill

Mr. Chairman and members of the Committee, my name is Dr. James E. Mulvihill. I am Vice-president for Health Affairs at the University of Connecticut Health Center and Professor of Periodontics in the School of Dental Medicine. I appreciate having this opportunity to present testimony regarding the fiscal 1984 budget for the National Institute of Dental Research (NIDR) and respectfully request that the full text of my testimony be included in the record.

I am appearing on behalf of the American Association for Dental Research (AADR), of which I am a member. The membership of the AADR includes more than 3,000 scientists in a variety of basic science and clinical disciplines located in universities, research institutes, hospitals, and industrial laboratories across the country. Our common aim is to determine the causes of the major diseases which affect the teeth and orofacial region of the body, and to seek ways of preventing them. The Organization, which is headquartered here in Washington, would be pleased to make its resources available to members of Congress and their staffs.

For most people in this country, oral diseases such as caries and periodontal disease continue from early childhood until death. Dental diseases, in fact, constitute the most prevalent health problem in the Nation.

The monetary cost to society as a result of oral diseases is high in terms of days lost from work, reduced productivity, and treatment. The annual out-of-pocket cost of these diseases is estimated to be in the range of $18 billion.

Although the National Institute of Dental Research is the smallest institute at NIH, we believe it has made significant progress in developing new knowledge about oral diseases. This is illustrated by the following examples:

> **Caries:** Results published during the past year show that tooth decay among schoolchildren has decreased in the range from 32% to 50%. The causes of this reduction are believed to be the multiple use of fluorides, improved dental hygiene, and better nutritional habits and diet. It is further believed that this reduction will increase to about 75% in the years ahead.
>
> **Periodontal (Gum) Disease:** Research on the reaction of the immune system in periodontal disease shows:
>
> > that specific bacteria cause periodontal diseases. These bacteria induce host defense reactions which destroy tissue around the teeth; and
> >
> > that the body can mount an antibody response to these bacteria.
>
> These findings provide the dental research community with leads for therapies such as antibacterial agents to combat periodontal disease. This work takes us to the threshold of controlling this insidious disease.

Restorative Materials: Over the last 10 years, a variety of new restorative materials has been discovered and introduced into the practice of dentistry. These materials are less expensive and more durable than those previously used. For example, plastic materials--commonly referred to in the dental field as composites--are now widely used, replacing silicates, which had a short useful life. Composites are also now making inroads toward replacing amalgams.

Potential Areas for Dental Research

Mr. Chairman, although the dental research community has made considerable progress in developing new knowledge about oral diseases, the potential for even greater understanding and new discoveries is high.

For example:

> New knowledge is continually being developed about **periodontal (gum) disease**:
>
> > New diagnostic tests are being developed which will permit dentistry to identify the disease at earlier stages, thus permitting better treatment. These tests will also permit researchers to closely monitor the various stages of this disease. In addition, scientists are studying regeneration of periodontal tissue for therapy following destruction by periodontal disease.
>
> Research is continuing in the area of **congenital malformations.** Researchers are beginning to identify substances which lead to facial malformations, and they are also identifying susceptible family lines. It is hoped that this research will lead ultimately to preventive measures that can be used by dental practitioners.
>
> The dental research community is taking the lead in conducting pain research, which will be beneficial to both the medical and the dental fields. This research is providing new concepts in the understanding of pain and how it is controlled by the body.

Many other highly promising areas of research exist, but I will not detail them at this point. However, I would like to say that many aspects of dental research are reaching the point where they need study in a clinical setting.

Clinical research projects should be developed and funded for a number of years adequate to ensure the development of a core of clinical investigators sufficient to allow for a transition of knowledge from the laboratory to the human testing phase.

It is our belief that a successful research program requires a balanced effort--namely, basic research, applied research, training, and technology transfer. The NIDR budget is deficient in that funds for multi-disciplinary dental research carried on at the dental centers have been reduced, and Research and Development contracts--our major source of technology transfer--have also been cut. Thus, we urge the Committee to restore funds for these important areas.

In light of the magnitude of the problems of oral disease, and the potential for significant breakthroughs in treating and preventing these diseases, we respectively recommend a funding level for NIDR of $94,091,000 in fiscal year 1984. Mr. Chairman, the NIDR is the smallest Institute of NIH. For you review, I have attached a chart which shows how this Institute has lost purchasing power over the last decade. If this trend continues, many research opportunities will be lost.

We urge the members of this Committee to consider these facts as they mark up the 1984 Appropriations for NIDR.

We would also urge the Committee to provide adequate support for the Division of Research Resources, which provides support for sophisticated laboratory instrumentation so important to the mission of dental research.

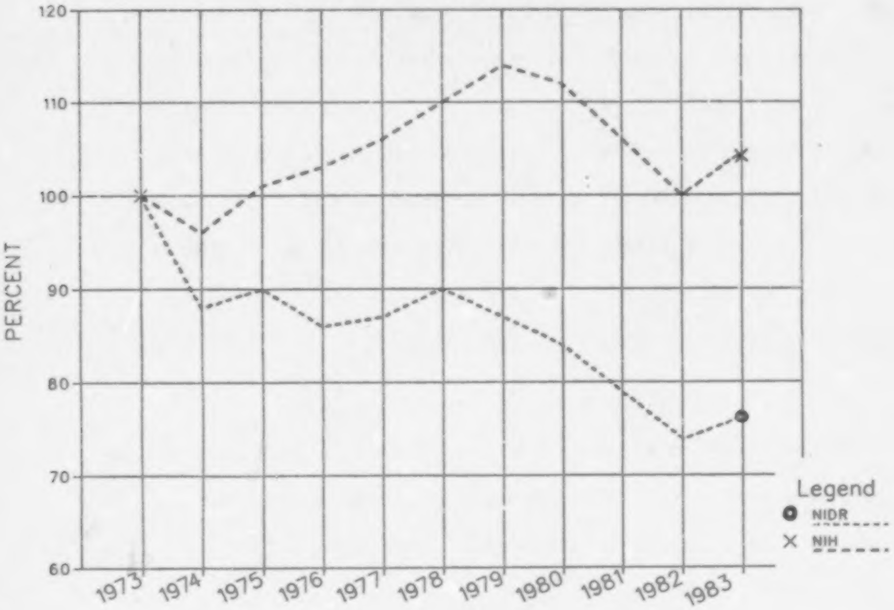
We will be happy to answer any questions.

AMERICAN ASSOCIATION FOR DENTAL RESEARCH
PROPOSED 1984 BUDGET FOR
THE NATIONAL INSTITUTE OF DENTAL RESEARCH

To achieve the aforementioned dental research goals, the following 1984 budget for the National Institute of Dental Research is recommended:

Research Grants	Number	Amount (in thousands)
Competing	175	$ 17,500
Non-competing	253	25,291
TOTAL		$ 42,791
Research Centers		$ 12,000
Other Research		2,500
Training		5,000
R & D Contracts		5,000
Intramural Research		17,900
Direct Operations		7,200
Program Management		1,700
TOTAL		$ 94,091

NIDR AND NIH ..PPROPRIATIONS
FY 73 – 83
IN CONSTANT DOLLARS



STATEMENT OF THE AMERICAN DENTAL HYGIENISTS' ASSOCIATION

Introduction

The Association wishes to express its views on the President's fiscal 1984 budget request for activities administered by the Public Health Service agencies of the Department of Health and Human Services.

The American Dental Hygienists' Association represents licensed dental hygienists who provide preventive oral health services within the dental care delivery system. Dental hygienists, as preventive care specialists, provide oral health care utilizing the highest professional knowledge, judgment and ability as specialists in oral health promotion and dental disease prevention. Dental hygienists use every available opportunity to increase public understanding of oral health practice and to provide oral health education to their patients.

The Association's Government Affairs Division has carefully studied the President's fiscal 1984 budget request for agencies of the Department of Health and Human Services. In the statement which follows, our comments and recommendations to the Committee will be focused upon budget requests for the following agencies of the Public Health Service: National Institute of Dental Research, Center for Disease Control, certain programs administered by the Office of the HHS Assistant Secretary for Health and programs administered by the Bureau of Health Professions of the Health Resources and Services Administration.

National Institute of Dental Research

The Association has a vital interest in the research activities of the National Institute of Dental Research and urges the Appropriations Committee to provide sufficient funds in fiscal 1984 to maintain the current schedule of activities of the Institute, so that the disease of the oral cavity can be reduced substantially, if not eliminated or prevented to a substantial degree. The Association strongly supports the ongoing intramural program of the Institute, conducted in eight laboratories and in a dental clinic in the NIH Clinical Center, and the extramural program conducted in more than 150 educational institutions and academic research centers. The extramural program administers projects which include research in dental caries, periodontal diseases, craniofacial anomalies, nutrition, restorative materials and pain control. Since its establishment, a major objective of the dental institute has been to study the biology of dental plaque and its causal relationship to dental decay. While the prevalence of dental decay has been decreasing in recent years, dental caries is still the most universal among all human diseases. Of equal importance among the Institute's priorities is the study of periodontal diseases (diseases developing in the soft tissues of the mouth), especially to develop diagnostic, therapeutic and preventive procedures aimed at arresting the disease completely.

The dental institute has set its priorities for further research activities in 1984 which include: studies in the etiology and pathogenesis of periodontal diseases, continuation of research to reduce or eliminate pain associated with acute and chronic illness, the epidemiology of oral diseases and conditions, the prevention of periodontal disease, the prevention of tooth root surface decay, and extension of studies on herpes simplex virus type 1.

The Association believes that the dental institute officials and professional staff have set sound and realistic goals and priorities for 1984 and 1985 and urges the Appropriations Committee to assure that adequate funds will be available to carry them out.

The Association recommends that an appropriation of not less than $80,600,00 be approved to support the 1984 dental institute's intramural and extramural programs. This request is $1,617,000 higher than the 1983 appropriation but in constant dollars which allow for inflation, it is $1,079,000 lower. The Association believes that this request for 1984 funding for the Institute's activities is commensurate with the priorities and goals which its officials have set forth.

Center for Disease Control (CDC) - Water Fluoridation Program

As recently as February, 1983 the Public Health Service's Surgeon General, in a formal statement to health officials urged adoption of fluoridation of public water systems as one of the most cost efficient mechanisms to improve the nation's oral health and prevent and reduce the incidence of oral disease. In this statement, Dr. C. Everett Koop, M.D. observed that "Fluoridation of community water supplies to reduce dental disease is an excellent example of a highly effective and efficient preventive method which offers a potential benefit to nearly everyone."

The Association is gratified that this Surgeon General, as many of his predecessors have done, "reaffirms (the Public Health Service) strong endorsement for fluoridating community water supplies to an optimum level . . . . . and stresses that this preventive measure is the single most important commitment that a community can make to the oral health of its children and to future generations".

The record will show that the Association shares and strongly supports this view and commends the current Surgeon General for reaffirming the longstanding support of the Public Health Service of this preventive oral health program. It is therefore most unsettling to us to learn that in the President's 1984 budget request, the fiscal 1983 $1 million dollar budget for the CDC fluoridation technical assistance program and staff has been eliminated. Again, we observe that despite all we have been reading about the Administration's commitment to disease prevention and health promotion initiatives one of the most commonly recognized, successful health promotion/health protection programs administered by the CDC is to be eliminated.

The Association is confident that the Appropriations Committee will quickly recognize the inconsistency of the Administration's meritorious verbal commitment to health promotion initiatives and its penurious approach to funding such activities. The failure to continue the technical assistance fluoridation program at the CDC is not just inconsistent, it is negligent. We believe that Congress should override the budget makers of OMB and restore the 1983 fluoridation program of the Center to a level of not less than $1.5 million -- the 1983 level of funding this line item, plus an allowance for inflation.

Office of the Assistant Secretary for Health (OASH)

Among its administrative responsibilities for some of the major agencies which comprise the U.S. Public Health Service (PHS) -

e.g., Food and Drug Administration, Health Resources and Services Administration, the National Institutes of Health, etc. - OASH has daily responsibility for health promotion initiatives and the national centers for health services research and health statistics. The President's fiscal 1984 budget indicates that OASH will assume additional responsibility for administering four health block grants, administered in 1982 and 1983 by other PHS agencies.

The Association will limit its comments on OASH activities to the following: the Preventive Health and Health Services block grant, since it includes funding for state water fluoridation programs and to the extramural research programs administered by the National Center for Health Services Research (NCHSR).

In 1981, Congress provided $93 million to fund the Preventive Health and Health Services block grant; in 1983 the funding level was reduced to $86.3 million. The President's fiscal 1984 budget recommends a further reduction to $85.3 million. Considering that this grants program includes funding to support state programs which also include: home health incentive grants, rat control, health/education risk reduction, hypertension, emergency medical services and rape crisis counseling, the Association is concerned that when the states set their spending priorities, existing community and school water fluoridation programs in many states may become victims of the governors' or legislatures' budget ax. Data are already coming in that indicate fluoridation programs are not faring well in the state block grants priority list. A recent survey ordered by HHS reports that in 4 of 5 states involved, fluoridation programs were either cut back or terminated.

It is our view, which we hope the Appropriations Committee will share, that all of the Administration's language about health protection and disease prevention does not match with the "numbers" for the block determined by staff of the Office of Managerment and Budget. While the Administration expects the states to assume responsibilities for a vast array of programs, formerly administered by PHS agencies at the federal level, it is recommending that somehow they do this with less. As Commander Spock of Star Trek fame would probably say, "This is illogical!" We agree and we believe the Committee will also agree.

The Association recommends that the Preventive Health and Health Services block grant be increased from the President's fiscal 1984 request of $85,300,000 to $100,000,000. The Association would be gratified to see language included in the Committee report which would call attention to the high cost-to-benefit ratio of community and school water fluoridation programs as cost-effective disease prevention and health protection strategies.

In reviewing the President's fiscal 1984 budget for the National Center for Health Services Research (NCHSR), the Association recognizes that funding levels between 1983 and 1984, with an addition in 1984 of $1.2 million for inflation, will permit this agency to carry out its ongoing primary research in the delivery of health services. It is our view, however, if the Administration's interest in containing and reducing health care costs were real, the NCHSR budget should be substantially increased. There is a vast need to conduct research in the role of competition and productivity in the health market place, as the President's budget defense statement observes. However, the agency's 1984 budget, held to 1983 funding levels essentially, is inadequate for the tasks it is supposed to undertake. There can be no fundamental change in the manner in which health care services are delivered, if research into new delivery modes cannot be funded.

The Association urges that the 1984 request for NCHSR budget be increased from $17.6 million to $20 million, so that at least some new health services research studies can be added to those currently funded in the extramural program of the Center.

Bureau of Health Professions (BHPr) - Health Resources and Services Administration (HRSA)

Among the four bureaus which comprise the Health Resources and Services Administration, the Association's comments on fiscal 1984 appropriations will be focused primarily on the funding requested for the Bureau of Health Professions. An analysis of the President's budget indicates that the BHPr is scheduled for a $60 million cut, compared with fiscal 1983 appropriation. We believe that a 32 percent reduction in 1984 of this Bureau's budget is extreme and unacceptable. It is our understanding that a reduction of staff will also be of the magnitude of 20 percent.

As the Appropriations Committee well knows, BHPr is an agency which administers health professions' student and institutional financial assistance, student loans and scholarships, financial need scholarships, minority school support, etc. In the past three years support for health professions students and educational institutions has been on a sharp, down hill spiral, to a point that seems to suggest an abdication of this function by the federal government.

Over the past three years budget reductions, staff reductions, program terminations have gone on relentlessly, if not brutally.

The dental hygiene and dental professions have watched the gradual erosion of the dental health programs and dental staff of BHPr approach the lowest all-time level in recent history. The dental health focus in HRSA and BHPr is so nominal that it is nearly nonexistent at this very moment.

The Association believes that the Appropriations Committee will share its concern that the function performed by BHPr and its divisions have been cut back and impaired, almost to a point of no return. We urge the Committee to continue BHPr funding 1984 at the 1983 level of $189,950,000, adding an additional $10,050,000 to provide for additional special initiatives and disadvantaged assistance program. We hope that the Committee will develop report language urging that the current level of 316 staff members of BHPr be maintained and that no further reductions in force be authorized. The total request for BHPr in 1984 should be $200,000,000.

In special reference to the dental staff of the Division of Associated and Dental Professions, we urge the Committee to emphasize the need to maintain a dental health program focus in the Bureau and the newly reorganized Division of Associated and Dental Health Professions.

The proposed increase in the fiscal 1984 budget, in support of the Health Professions Special Education Initiative program, from $2,000,000 in 1983 to $7 million, is commendable. In particular, the Association supports the proposed increase for the grants and contracts program from $800,000 to $1,055,000, for the education and training of allied health personnel for health promotion and disease prevention. Also, the Association commends the increased funding recommended to establish regional geriatric education centers from $900,000 in 1983 to $2,353,000.

It appears that these two new BHPr initiatives will help to reverse the downward trend of the last three years in providing federal support for health and allied health education institutions. We welcome this change and urge the Appropriations Committee to encourage and support the Administration in this instance to match its disease prevention/ health promotion rhetoric with adequate funding support. As noted elsewhere in this statement, such a match-up has been more the exception than the rule.

In a final comment on the 1984 BHPr budget, the Association wishes to record its continuing support for the Health Professions Analytical Studies and Reports Program. The Association and counterpart health and allied health professions, are the beneficiaries and user consumers of many useful studies relating to supply, distribution and utilization of health manpower. The expertise of the staff of the Division of Health Professions Analysis has long been recognized and appreciated by health professions administrators, educators and research scienists.

The Health Professions Analytical Studies and Reports program covers a wide spectrum of analysis relative to health care financing, educational environment, geographic distribution of practitioners, such as dentists and dental hygienists and the relationships between dentists and dental hygienists and analysis of the dental hygiene work force; e.g., the 1979 "Survey of Dental Hygienists' Life Cycle Labor Market Participation". In addition, the Division of Health Professions Analysis provides the critical data which serves as the basis for the BHPr's annual report on the status of health and allied health professions to the Congress and to the President.

The 1984 budget rationale statement indicates that the proposed $650,00 increase and budget authority of $3,612,000 for the analytical studies and reports activity will support 21 contract awards and provide for costs of intramural activities. The Association cannot critically evaluate whether the amounts requested in fiscal 1984 will be sufficien to accomplish the activities described. However, as we have commented in another section of this statement, we urge the Appropriations Commit tee to maintain funding levels of the BHPr at not less than fiscal 198 levels, or higher when justified, as in this analytical studies and reports program.

In particular reference to the Division of Health Professions Analysis, the Association reiterates its recommendation that no further staff reductions be authorized by the Committee.

Conclusion

The Association welcomes this opportunity to express its views and recommendations on the proposed 1984 budget for agencies of the Public Health Service. We are aware that the Appropriations Committee must cope with difficult and complex decisions in sorting out the priorities of Congress, as opposed to those recommended by the Administration. We urge the Committee to report an appropriations bill in this session, so that the frequently used mechanism of a continuing resolution will not again be necessary in fiscal 1984.

SUBCOMMITTEE RECESS

Senator ANDREWS. The subcommittee will now stand in recess until 8:30 a.m. tomorrow morning, April 29, when we will convene again in this room to continue public witness testimony on the Department of Health and Human Services fiscal 1984 budget.

[Whereupon, at 10:38 a.m., Thursday, April 28, the subcommittee was recessed, to reconvene at 8:30 a.m., Friday, April 29.]

DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 1984

FRIDAY, APRIL 29, 1983

U.S. SENATE,
SUBCOMMITTEE OF THE COMMITTEE ON APPROPRIATIONS,
Washington, D.C.

The subcommittee met at 8:30 a.m., in room SD–116, Dirksen Senate Office Building, Hon. Lowell P. Weicker, Jr. (chairman) presiding.

Present: Senators Weicker and Proxmire.

NONDEPARTMENTAL WITNESSES

Senator WEICKER. The subcommittee will come to order. Today we're going to continue the public witness hearings on the fiscal year 1984 budgets for the National Institutes of Health, and the Alcohol, Drug Abuse, and Mental Health Administration.

Again, I would like to remind the witnesses that are here that this elaborate system is to save me the embarrassment of having to rap a gavel. We will have almost 200 witnesses, and in order to accommodate everybody, it's necessary to keep to the rather narrow time constraints.

This young lady to my right is the activator of the mechanism. I found out last night she went to the University of Virginia, which is the reason why it's been handled so well during the past several days. In any event I would appreciate if you would just have consideration—not for me; I'll sit in this chair as long as needs be—but rather for the other witnesses.

STATEMENT OF HON. JAMES ROOSEVELT, PRESIDENT, NATIONAL COMMITTEE FOR RESEARCH IN NEUROLOGICAL AND COMMUNICATIVE DISORDERS

ACCOMPANIED BY:

DR. STANLEY VAN DEN NOORT, VICE CHAIRMAN OF NATIONAL COMMITTEE FOR RESEARCH, NEUROLOGIST AND DEAN OF THE MEDICAL SCHOOL, UNIVERSITY OF CALIFORNIA AT IRVINE, AND PAST CHAIRMAN, MEDICAL ADVISORY BOARD, NATIONAL MULTIPLE SCLEROSIS SOCIETY

DR. ROBERT RUBEN, PROFESSOR OF OTORHINOLARYNGOLOGY AND PEDIATRICS, ALBERT EINSTEIN COLLEGE OF MEDICINE, YESHIVA UNIVERSITY, CHAIRMAN, DEPARTMENT OF OTORHINOLARYNGOLOGY, ALBERT EINSTEIN COLLEGE OF MEDICINE

Senator WEICKER. Our first witness this morning is an old friend, James Roosevelt, president of the National Committee for Research in Neurological Communicative Disorders, and a former Member of Congress. It's just a great pleasure to have you before the committee. Please go ahead and proceed in any way you want.

Mr. ROOSEVELT. Mr. Chairman, may I ask if Dr. Ruben and Dr. van den Noort, who are my chairman and vice chairman, can——

Senator WEICKER. Sure.

Mr. ROOSEVELT. Thank you, Mr. Chairman. I certainly appreciate this opportunity to testify in my capacity as president of the National Committee for Research in Neurological and Communicative Disorders. We're known as NCR for short.

NCR is a coalition of 62 major voluntary and professional health organizations dedicated to the goal of increased public support for research in neurological and communicative disorders.

Our list of member voluntary associations reads like a list of the most debilitating of the chronic diseases and handicapping conditions that threaten each and every one of us as we progress from young adulthood to senior citizens.

They threaten our newborns when we become parents and grandparents, and our children and grandchildren when they mature and grow to adulthood themselves.

The leaders of NCR member organizations are persons who frequently have had a tragic personal exposure to these awful conditions and diseases. Others are professionals—physicians, scientists, researchers—who have dedicated their professional lives to solving the great mysteries of how the human body functions. From vastly disparate backgrounds and experiences the members of NCR have come together to petition their Government to perform that role which the Federal Government is uniquely qualified to perform, that is the marshaling of national resources and effort to uncover the causes and to develop the cures for these neurological and communicative disorders.

Mr. Chairman, let me explain my own interest in this area. If I may, I'd point out that my father, Franklin D. Roosevelt, is well remembered in this country as a man who had a great impact on the Presidency of the United States, a man who seemed invincible as he carried out his duties of office during very tumultous times.

He was a man confined, however, to a wheelchair for the majority of his adult years. I would imagine that few people have ever thought of my father as a paraplegic and as having suffered a major disappointment in his life. However, he experienced a disappointment that caused him physical pain and emotional distress. That disappointment came from the realization toward the end of his life that no matter what research or physical therapy techniques had been developed during his Presidency he would never achieve his dream of walking again.

Letting go of that dream required a really emotional adjustment. It wasn't easy. Since he was my father, I shared in his disappointment. Therefore, you can imagine my enthusiasm when I was approached to become president of this organization of active, caring individuals to help them in their organization secure an increased support for central nervous system and brain research, which has as one of its potential results spinal cord regeneration, which would have helped my father.

The 600 disorders of the nervous system afflict one out of every five Americans. The disorders impair memory, intelligence, and the control of every body system. Dementia, stroke, paralysis, deafness, and the mental impairment of children are but a few of the disorders which describe its impact.

Mr. Chairman, my scientific friends tell me that the 1980's will be known in medical research as the decade of the neurosciences, a decade in which we will finally understand the workings of the human brain.

At the National Institutes of Health, NINCDS, the Neurology Institute is the focal point for this national effort. The NINCDS should at the very least be given the opportunity to maintain the present momentum of neuroscience research. Of equal importance, it seems to me, it should be permitted to take advantage of the innumerable additional scientific opportunities that are now available.

I am confident that given this opportunity in the 1980's NINCDS will be able to accomplish the prevention and the treatment of disorders of the brain and nervous system similar to what has been accomplished in the 1970's for heart disease.

The organizations I represent, Mr. Chairman, and of course I as a private individual, urge this subcommittee to set as its goal 3 years hence a budget for the NINCDS of $600 million. This budget comparable to that of the Heart Institute will provide the stimulus and the opportunity for meeting our national purpose of insuring that disorders of the brain and the nervous system and hearing will be properly addressed.

Mr. Chairman, may I just add at that point that that's a lot of money, and if you just put in tons of money, it doesn't mean much. It means, can it be used?

I personally have spent quite a bit of time out at NIH looking into seeing what they could do, and my two colleagues who are with me today I think will testify that in the private sector if there was more money available through the National Institutes of Health, that we would be able to put it to work immediately.

So it is not a dream, it's a practical thing where we would not waste a penny of appropriated money.

In 1983, $30 million additionally is required over the President's budget, merely to maintain the Institute's 1983 effort.

However, Mr. Chairman, I would hope that the subcommittee would also agree that a 1984 budget of $392 million for NINCDS would be a reasonable base to initiate and begin the 3-year endeavor which I have described.

The brain is what we are. The opportunity to understand it and prevent disorders in children and adults is now available.

PREPARED STATEMENT

I trust, Mr. Chairman, the subcommittee will join us in seeing to it that the NINCDS is permitted to achieve this goal. I'm talking about more than 50 million Americans, more than 1 in 4.

Thank you very much, sir.

[The statement follows:]

STATEMENT OF JAMES ROOSEVELT

Thank you, Mr. Chairman. I appreciate this opportunity to testify in my capacity as president of the National Committee for Research in Neurological and Communicative Disorders, NCR. NCR is a coalition of 62 major voluntary and professional health organizations dedicated to the goal of increased public support for research in neurological and communicative disorders. Our list of member voluntary associations reads like a list of the most debilitating of the chronic diseases and handicapping conditions that threaten each and every one of us as we progress from young adulthood to senior citizens, that threaten our newborns when we become parents or grandparents, and our children and grandchildren when they mature and grow to adulthood themselves. The leaders of NCR member organizations are persons who frequently have had a tragic personal exposure to these awful conditions and diseases. Others are professionals—physicians, scientists, and researchers—who have dedicated their professional lives to solving the great mysteries of how the human body functions. From vastly disparate backgrounds and experiences, the members of NCR have come together to petition their Government to perform that role which the Federal Government is uniquely qualified to perform, a marshaling of national resources and effort to uncover the causes and to develop the cures for these neurological and communicative disorders.

Mr. Chairman, let me explain my own interest in this area. I must point out that although my father, Franklin D. Roosevelt, is well remembered in this country as a man who had a great impact on the Presidency of the United States and the world, a man who seemed invincible as he carried out his duties of office during very tumultous times, he was a man confined to a wheelchair for the majority of his adult years. I would imagine that few people have ever thought of my father as a paraplegic and as having suffered a major disappointment in his life. However, he experienced a disappointment that caused him physical pain and emotional distress. That disappointment came from the realization toward the end of his life that, no matter what research or physical therapy techniques had been developed during his Presidency, he would never achieve his dream of walking again. Letting go of that dream required a real emotional adjustment for my father; it wasn't easy. Since he was my father, I shared in his disappointment. Therefore, you can imagine my enthusiasm when I was approached to become president of this organization of active, caring individuals to help them in their organization securing increased support for central nervous system and brain research which has, as one of its potential results, spinal cord regeneration.

The mission of the National Institute of Neurological and Communicative Disorders and Stroke is to learn both how the brain and nervous system work and how to prevent and treat the devastating disorders that result from its illnesses.

The 600 known disorders of the nervous system afflict one out of every five Americans. The disorders impair memory, intelligence, and the control of every body system. Dementia, stroke, paralysis, deafness, and the mental impairment of children are but a few of the disorders which describe its impact.

Mr. Chairman, my scientific friends tell me that the 1980's will be known in medical research as the year of the neurosciences—the year in which we will finally understand the workings of the human brain. At the National Institute of Health, the NINCDS, the Neurology Institute, is the focal point for this national effort. The NINCDS should at the very least be given the opportunity to maintain the present momentum of neuroscience research; of equal importance it should be permitted to take advantage of the innumerable additional scientific opportunities that are now available. I am confident that given this opportunity, in the 1980's, the NINCDS will be able to accomplish preventing and treating disorders of the brain and nervous system what has been accomplished in the 1970's for heart disease.

The organizations I represent, and I as a private individual, urge this subcommittee to set as its goal 3 years hence a budget for the NINCDS of $600 million. This budget comparable to that of the Heart Institute will provide the stimulus and the opportunity for meeting our national purpose of insuring that disorders of the brain, the nervous system, and hearing will be properly addressed.

In order to achieve this national purpose, in 1984 an additional $30 million is required over the President's budget merely to maintan the Institute's 1983 endeavor. However, Mr. Chairman, I would hope that the subcommittee would also agree that a 1984 budget of $392 million for NINCDS would be a reasonable base to initiate the 3-year endeavor which I have described.

The brain is what we are. The opportunity to understand it and prevent disorders in children and adults is now available. I trust you will join us in seeing to it that the NINCDS is permitted to achieve this goal.

Senator WEICKER. Thank you very much. On the research centers was there any change here, do you know, in terms of NINCDS? I believe this is to try to bring the grants up to 5,000 and if that's done, two of the following would not be funded: the Research Center in Cerebrovascular Disease, Cornell University Medical Center; pathogenesis and treatment of multiple sclerosis, Yeshiva University; and Center for Clinical Research in Epilepsy, University of Washington.

Maybe your two professional colleagues would like to comment upon the impact of the closings of those institutions.

Mr. ROOSEVELT. Stan, do you want to start? Dr. van den Noort, the dean of the University of California at Irvine Medical School, sir.

Senator WEICKER. OK.

Dr. VAN DEN NOORT. Those are three very important centers. I'm familiar with each of them and their closing would be most unfortunate.

Certainly the best thing to do would be to have the incremental increase in the budget that Mr. Roosevelt is asking for and to preserve those centers.

And it is true, I think, that the individual grant priorities are the most important thing, and we have large numbers of investigators who currently are not doing research that could be funded, and that certainly has the highest priority.

I would agree with the NIH in taking the approach that they described there, if they must remain within the planned budget; however, an incremental increase in the budget would be a far more desirable alternative.

Dr. Ruben?

Dr. RUBEN. I will not speak about Yeshiva because that's where I'm from—that would be a little too parochial, although somewhat chauvinistic.

I think what you have articulated, sir, is just the tip of the iceberg because as we have sat down and looked at the numbers more intimately at the NINCDS, there are several other things that are happening.

In order to maintain the floor of 5,000 grants which in terms of the NINCDS is approximately 500 grants, they must do several things: they must cut not only program projects in clinical centers, they must cut training; they must also cut intramural research.

In addition, what was new yesterday becomes old today. A grant which you may have been given yesterday for a substantive approach on how to think, on how to live, next year is now an old grant, and you'll be cut 15 or 20 percent in order to fulfill this rather empty gesture of numbers which the Office of the Budget has promulgated upon the NINCDS. There are some more even more insidious problems in that—which we may not get into—there are substantive areas to now go in and do things which can make people much better.

The Lasker Award was given to one of the intramural scientists who has now found the enzymes to conquer a number of congenital diseases.

The problem with aging, called Alzheimer's disease, senile dementia, is not a necessary given of this life. There is the possibility of doing something here: both what has been found within intramural, which will be cut, and extramural, where there will be grants but not funded enough. There are people out there who can do this work if they can get the funds.

In my own area of communicative disorders and hearing, the essence of being old and not hearing again is not a given. There are things that can be done, there are people out there who are producing the peer review work in order to have it done.

Intramurally, there is a program slated to look into communicative disorders. This has not been filled yet. If there is not the substantive million dollar increase, this won't have to be cut, this will just lie fallow and will be aborted.

Senator WEICKER. Thank you very much. Incidentally, for the record, I wonder if both of you will identify yourself for the reporter.

Mr. VAN DEN NOORT. I'm Dr. Stanley van den Noort, vice chairman of NCR. I'm a neurologist and a dean of the medical school at the University of California at Irvine and past chairman of the Medical Advisory Board of the National Multiple Sclerosis Society.

Dr. RUBEN. I'm Robert Ruben, I'm professor of otorhinolaryngology and pediatrics at the Albert Einstein College of Medicine, Yeshiva University, and I'm chairman of the department of otorhinolaryngology at Albert Einstein. I also have the privilege of being the chairperson of the National Committee for Research.

Senator WEICKER. Gentlemen, Jim, thank you very, very much. It's always a delight to have you here and I think you've articulated the problem very well.

I can only assure you that I will do my best. I think my attitudes are pretty well known in this area. I see so much money being spent on destruction, so little money spent on life, and I think we both know what the United States does best, but it doesn't come cheap.

Mr. ROOSEVELT. Thank you very much, Mr. Chairman, and thank you again for the opportunity of seeing you personally again.

Senator WEICKER. Thank you.

STATEMENT OF ANN C. BELL, ASSISTANT TO THE PRESIDENT, AMERICAN PARALYSIS ASSOCIATION

Senator WEICKER. Ann Bell, assistant to the president, American Paralysis Association. Ann, nice to have you here.

Ms. BELL. Mr. Chairman, thank you for your time and consideration of my statement on behalf of the American Paralysis Association and as a member of the National Committee for Research in Neurological and Communicative Disorders.

I am here on behalf of the APA to express support for the statement made by the Honorable James Roosevelt requesting funding at the level of $392 million, for fiscal year 1984, for the National Institute of Neurological and Communicative Disorders and Stroke under the National Institutes of Health.

Specifically, I want to address the status of spinal cord injury regeneration and research as viewed by the APA and why our private sector initiative can only be successful by working on the base of ongoing Federal Government research in this area at NINCDS.

Spinal cord paralysis afflicts an estimated 500,000 people in the United States with another 15,000 to 20,000 individuals added to the list of victims annually. The average age of these victims is 19 and most are injured as a result of motor vehicle or sports accidents, the consequences of which are partial paralysis—paraplegia—or complete paralysis—quadriplegia.

Along with loss of ability to use arms, hands, and legs, there is almost always loss of sexual function and of bladder and bowel control. Most of these victims also suffer from spasticity and from intense and almost continuous deep-seated pain.

Spinal cord injury is truly a dread crippler, subjecting its victims and their families to much suffering. The survival of paralyzed patients is beginning to approach that of the normal population due to more effective medical care. Consequently, many spinal cord injured people can only look forward to a longer, severely impaired life.

Physicians have counseled victims and their families to accept a lifetime of confinement to bed or wheelchair. Even today, many doctors advise that there is no possibility of recovery and recommend rehabilitation and physical therapy as the only measures available to help alleviate some of the difficulties associated with a life of inactivity.

Now there is hope. Progress in understanding the complex nervous system and the therapeutic effects of certain pharmacological and trophic agents has caused scientists to reevaluate their previous conclusion that the central nervous syteam cannot be healed. With better understanding of the intricate relationships existing among the chemical, pharmacological, and electrical components of the central nervous system, some well informed scientists are convinced that a cure for spinal cord paralysis is not only possible, but highly probable.

The American Paralysis Association was organized in 1982 by parents and relatives of spinal cord paralyzed persons, medical research experts, and concerned citizens. It is dedicated to finding a cure for spinal cord paralysis. Its objective is the stimulation, encouragement, and support of applied research directed toward the earliest possible cure. To that end, in just 1 short year we have become the largest private funder of this spinal cord injury research in our country today.

Seizing upon the early shreds of evidence that a cure for spinal cord paralysis might be possible, the APA embarked upon an ambitious program to find and perfect a cure by establishing communications with health agencies, scientists, physicians, researchers, Government agencies, and the Congress of the United States.

The message was clear: Evidence suggests that the cure of spinal cord paralysis is not hopeless, that modern technology and medical science will bring about a cure for injured spinal cords.

The message has been heard. In recent years, the U.S. Government has increased funding for research on spinal cord injury and regeneration of the central nervous system.

The National Institutes of Health, the Veteran's Administration, and the National Institute for Handicapped Research have all demonstrated an increasing awareness of the potential for finding a cure.

More and more physicians and medical researchers are accepting the premise that a cure for spinal cord paralysis is possible. Successful research in this area will benefit victims of other neurological disorders as well.

Much of spinal cord regeneration research sponsored by Government agencies is not focused on the application to human cure. Generally, it is basic research—a search for new knowledge—rather than research on techniques and procedures to cure human paralysis. This is where the American Paralysis Association can, working closely with NINCDS, make major advances in the fight to defeat this crippler.

By applying all of our resources and energies to the planning, execution, management, and control of a cohesive, carefully structured program of targeted research, the APA can and will speed the experimentation and testing necessary to perfect a cure.

APA can move more rapidly than Government-sponsored research. However, the APA effort must rest on a strong base of governmental research pointing the way to the most needed basic research to fill in the areas where knowledge is deficient.

The necessary groundwork has been laid for an all-out, well-planned effort and APA is well positioned to conduct this program. A largely volunteer organization, it has been able to accomplish a great deal with minimum overhead cost. Sponsoring directors are prepared to continue to a successful conclusion.

In conclusion, the American Paralysis Association knows where we are going—the destination being sought is clear: the discovery and perfection of a cure for the disabling effects of spinal cord paralysis. This is an ambitous goal, but with the rapid advances being made in modern technology and medical science, it is achievable.

But our plan can only succeed with our private sector initiative working hand in hand with the Federal Government through the National Institute of Neurological and Communicative Disorders and Stroke.

We at the APA as members of NCR certainly understand the financial constraints upon Congress in these times and agree completely with the statement made by Mr. Roosevelt with regard to the large spread between the $312 million minimum amount requested for NINCDS by the Consortium Concerned with the Developmentally Disabled and our maximum request for research in the amount of $392 million.

The American Paralysis Association, because of our one-dimensional research for cure program, certainly would like to see the maximum amount granted to NINCDS.

However, with this in mind and with the recognized economic conditions prevalent in our country today, we would urge you to please carefully consider our request for an increased amount above the $312 million so that all of us involved in private sector funding for research in neurological and communicative disorders may reach our goals of alleviating the personal tragedy and the enormous national expense of these disabling conditions.

Thank you.

PREPARED STATEMENT

Senator WEICKER. Ann, thank you very much. I appreciate your statement.

[The statement follows:]

STATEMENT OF ANN C. BELL

Mr. Chairman and distinguished members of the Subcommittee, thank you for your time and consideration of my statement on behalf of the American Paralysis Association (APA) and as a member of the National Committee for Research in Neurological and Communicative Disorders (NCR).

I am here on behalf of the APA to express support for the statement made by the Honorable James Roosevelt requesting funding at the level of $392,000,000 for fiscal 1984, for the National Institute of Neurological and Communicative Disorders (NINCDS) under the National Institutes of Health.

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Until very recently this condition was considered hopeless by most medical authorities. Physicians have counseled victims and their families to accept a lifetime of confinement to bed or wheelchair. Even today, many doctors advise that there is no possiblity of recovery and recommend "rehabilitation" and "physical therapy" as the only measures available to help alleviate some of the difficulties associated with a life of inactivity.

Now, there is hope. Progress in understanding the complex central nervous system and the therapeutic effects of certain pharamacological and trophic agents has caused scientists to re-evaluate their previous conclusion that the central nervous system cannot be healed. With better understanding of the intricate relationships existing among the chemical, pharmacological, and electrical components of the central nervous system, some well-informed scientists are convinced that a cure for spinal cord paralysis is not only possible, but highly probable.

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In conclusion, gentlemen, the American Paralysis Association knows where we are going -- the destination being sought is clear: the discovery and perfection of a cure for the disabling effects of spinal cord paralysis. This is an ambitious goal, but with the rapid advances being made in modern technology and medical science it is achievable. But, our plan can only succeed with our private sector initiative working hand in hand with the Federal Government through the National Institute of Neurological and Communicative Disorders.

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Thank you.

STATEMENT OF BARBARA GIRION, AUTHOR; REPRESENTING THE CONSORTIUM FOR CITIZENS WITH DEVELOPMENTAL DISABILITIES

Senator WEICKER. All right. Our next witness is Barbara Girion, representing the Consortium for Citizens with Developmental Disabilities.

Ms. GIRION. Mr. Chairman, I am pleased to have this opportunity to speak on behalf of the research task force of the Consortium for Citizens with Developmental Disabilities—CCDD.

My name is Barbara Girion. Professionally, I am known as an author of books for young children. Privately, I am a mother of three children and my son Eric was diagnosed as having epilepsy at the age of 12. He's 19 now, so we've had 7 years to live through a problem where basic medical research is ongoing and needed, and I've seen the results of it.

In 1981 I combined my professional life of a writer with my private life as a mother of a son with a problem and wrote a book entitled "A Handful of Stars," which is the story about a young person with epilepsy, and I have an autographed copy that I hope to leave with you when I finish my statement.

Senator WEICKER. Thank you very much.

Ms. GIRION. So I think this will show my sincere interest in disabilities and medical research.

The three Federal agencies known as the NINCDS, the NIMH, and the NICHD have had a strong impact on the lives of disabled people as they have provided many breakthroughs in the past decade.

On behalf of the task force, I would like to recommend appropriation levels for the next fiscal year. We recommend an absolute minimum of $312 million for the NINCDS budget and that will just about hold the research to last year's level.

The administration's recommendations of $310 million are unacceptable as that would cause a serious reduction in all the research levels. The task force does support the President's recommendation for NIMH of $172.1 million as an absolute minimum.

The task force also recommends $267.6 million for NICHD research and also recommends that appropriate language be inserted in the committee report reflecting the intent of Congress to increase MRDD research within the Center for Mothers and Children.

Up to now I've just been throwing numbers at you and the committee, but I'd just like to close by saying the dedication of my book reads: "For my son Eric, who faced it all with courage and grace."

And I'd like to thank you for the opportunity of speaking this morning on behalf of the task force. And I want to thank you in advance for your consideration of the needs of people with developmental disabilities to afford them a chance of a life that they can live with courage and grace, not only now but also a life of future dignity and productivity.

Thank you very much.

Senator WEICKER. Barbara, thank you very much.

[The statement follows:]

STATEMENT OF BARBARA GIRION

Mr. Chairman, I am pleased to have this opportunity to speak on behalf of the Research Task Force of the Consortium for Citizens with Developmental Disabilities (CCDD). Members of the Task Force are indicated on the cover page of this statement. The individuals we represent have disorders of the brain and central nervous system. The federal government has provided crucial leadership and resources in supporting research aimed at preventing, treating, and curing neurological disorders and mental illness. Three federal agencies are responsible for initiating, sponsoring and coordinating the wide range of basic and applied research projects. The prime federal agency responsible for biomedical research affecting developmental disorders is the National Institute of Neurological and Communicative Disorders and Stroke (NINCDS). The National Institute of Mental Health (NIMH) Research Program develops new approaches to the causes, diagnosis, prevention and control of mental illness. The National Institute of Child Health and Human Development (NICHHD) oversees research aimed at the prevention of mental retardation and other developmental disabilities. The knowledge gained, and the medications and treatment strategies developed from projects sponsored by these three agencies have helped millions of Americans to lead more independent and productive lives.

For over 20 years, research sponsored by NINCDS has brought us closer to fully understanding how the brain and nervous system work and why they malfunction. These two organs are the most vulnerable part of the human body during the developmental period. With knowledge gained from basic research NINCDS develops methods of treating neurological disorders. The ultimate goal is the cure and prevention of 600 such disorders.

The funds awarded by NINCDS, through both intramural and extramural grants, support a wide range of research activities. Among the projects supported by NINCDS are the following:

1) Researchers are studying the neurological processes that are the bases of autism, while others devise new approaches to teaching language to autistic children;

2) An intramural research scientist discovered the specific enzyme deficiencies responsible for a class of developmental disorders. Further research on replacement of the missing enzymes shows great promise of finding a cure and, hopefully, ways to prevent these diseases;

3) A project to assess pharmacological treatments for persons with cerebral palsy has noted improvements in movement under some drug regimens. Another grant funded a study on the efficacy of early physical therapy in the treatment of cerebral palsy;

4) A study examining possible variables affecting occurrence or development of learning disabilities has already shown a positive relationship between hyperkinetic-impulsive behavior at age seven and maternal ingestion during pregnancy of drugs containing caffeine.

These examples only begin to suggest the wide range of activities and positive results of research sponsored by NINCDS.

There is also a significant link between these diverse projects. Research has a cumulative effect; projects sponsored in one area will influence and reap rewards in another area. Studies indicating the causes of neurological deterioration suggest areas of further research to prevent such deterioration. Understanding the cause of a disorder is the first step to understanding how to prevent it.

Knowledge gained through NINCDS-sponsored experiments has led to the development of many successful treatments. Towards this end, NINCDS has fostered a productive partnership with the pharmaceutical industry. NINCDS researchers have gained new insight into rare developmental disorders requiring treatment with "orphan drugs." In cooperation with pharmaceutical companies, NINCDS is developing and evaluating orphan drugs that could be used to treat certain types of epilepsy. NINCDS plans to continue this productive relationship to sponsor development of drugs for other neurological disorders.

Continued progress in biomedical research cannot occur without skilled research personnel. The Institute's research training and research career development programs insure the availability of clinical investigators qualified to carry on, expand, and adapt research discoveries to tomorrow's needs.

The NINCDS accomplishments have enabled many developmentally disabled persons to lead productive, independent lives. Science has enabled us to prevent or cure many disorders, and new treatments have minimized the severity of many disabilities which cannot yet be prevented or cured. In order to continue this progress, the appropriation for NINCDS must be increased. The number of grants awarded by NINCDS has remained relatively constant over the past four years, but there is a 6.2% reduction in the current year. The Administration's recommended funding level for FY 1984 of $301 million, if adopted, would force a serious further reduction in the level of research. This reduction would result in fewer funded grants, lower funding for each grant, or both. Such a policy is both unwise and unacceptable.

The Task Force strongly recommends that the Congress appropriate at least $312 million to the NINCDS budget which will restore research to last year's level.

The purpose of the NIMH Research Program is to increase our knowledge of all aspects of mental illness and thus discover new methods of treatment and prevention. To achieve this goal, NIMH funds extramural research programs through grants, contracts, academic and research institutions, and other organizations. The intramural research program operates through laboratories located on the campus of the National Institute of Health (NIH) and the grounds of Saint Elizabeth's Hospital. NIMH-supported research comprises the bulk of research on serious mental illness being done in the United States, and such research is respected throughout the world. Research by NIMH-supported scientists has produced two Nobel Prize winners in recent years.

The President's FY 1984 extramural research request will support a total of 277 new and competing research project grants, an increase of 79 projects. The intramural research budget will support the current level of operations. Much needed increases in our understanding of major mental disorders of childhood and adolescence, including depression and autism, will be pursued, as will research in cognition and memory problems of aging.

The Task Force is pleased that the President has moved to replace the severe cuts in FY 1982, and recommend funding to accomplish the purposes indicated above. Because of chronic under-funding over the past decade, which has resulted in a substantial erosion in the constant-dollar support of extramural research, and barely staying up with inflation for the intramural program, the Task Force supports the President's recommendation of an appropriation of $172.1 million as an absolute minimum requirement for FY 1984.

The Center for Research on Mothers and Children of NICHHD contains the Mental Retardation and Developmental Disabilities (MRDD) Branch, the only federal research agency whose sole responsibility is research on mental retardation and other developmental disabilities. The MRDD Branch provides core support for the 12 national Mental Retardation Research Centers as well as Biomedical and Behavioral Research Grants to qualified researchers. Institute grantees have developed screening tests and treatments for some inherited metabolic disorders that cause mental retardation. As a result, newborns with certain disorders can now be identified at birth and early treatment can prevent retardation. In addition, improvements in prenatal care and delivery have reduced the incidence of mental retardation resulting from birth injuries.

The President's request of $257.3 million represents a two percent increase over the FY 1983 level. This small increase will result in an actual decrease next year when the rate of inflation is taken into consideration. Therefore, fewer research projects are likely to be funded next year.

Persons who are mentally retarded or otherwise developmentally disabled continue to require substantial assistance from governmental agencies in order to live. Therefore, the finding of cures and methods to improve the performance of developmentally disabled citizens is highly desirable, both in humane and economic terms. Increasing research efforts in this field could well lead to significant governmental savings in the future.

Therefore, the Task Force recommends $267.6 million for NICHHD research. The Task Force also recommends that language be inserted in the Committee Report reflecting the intent of Congress to increase MRDD research within the Center for Mothers and Children.

The Task Force wishes to thank you for this opportunity to express its view on the importance of continued federal support for medical and scientific research.

Senator WEICKER. I have one question for you.

Ms. GIRION. Surely.

Senator WEICKER. You've made recommendations for minimum funding levels. The previous witnesses referred to a maximum of $392 million. Have you reexamined your recommendations?

Ms. GIRION. OK. Ideally, $279 million would enable NICHD to continue their progress and would fund them for all of the research programs, so something in between that and what we're asking. We are holding with the President's minimum per NIMH and $395 million, yes, for NINCDS.

And that would take care of all the approved grant research programs that there are at the present time. So yes, ideally, that is what we would like to ask.

Senator WEICKER. Thank you very much. I appreciate it.

Ms. GIRION. Thank you.

STATEMENT OF LOUISE S. GLICKMAN, REPRESENTING THE NATIONAL INSTITUTE OF NEUROLOGY, COMMUNICATIVE DISORDERS, AND STROKE

Senator WEICKER. The next witness is Louise Glickman of New Orleans.

Ms. GLICKMAN. Mr. Chairman, I'm Louise Glickman. I am the mother of two children, Adam, age 12, and Laura, age 8, who are affected with Gaucher's disease, which is a rare enzyme deficiency being researched at the National Institute of Neurological and Communicative Disorders and Stroke.

It's a privilege for me to bring the facts about this little-known disorder to your attention by telling you their story—our story, really, because a chronic and debilitating illness such as theirs taxes and strains the physical and emotional fiber of every person within the family unit.

If you have ever accompanied a child, family member or friend to a hospital for emergency treatment, then you understand the feeling of helplessness, which is something that a mother like myself feels each and every day.

By allowing me to deliver this message here today, you are helping me to help my children and you are helping them to hope that their future may be brighter because of the promising research at NINCDS.

Adam and Laura are two bright and outgoing children who have the hopes and dreams of other children their age, but they are locked in the isolation of being different and in the fear of an unknown future.

They are small and thin with protruding bellies, due to their critically enlarged spleen. My daughter Laura has intermittent nosebleeds and both are prone to severe bruising, which is a constant embarrassment for them.

My daughter is asked by her classmates, "Why is it that you look pregnant?" And my son watches from the sidelines the sports activities of other children his age.

They are physically tired and they are emotionally frustrated, and their daily course is threatened by periodic bone crises which range in severity from a mild ache to pains of insurmountable intensities. Laura has been hospitalized twice with such infarcts where even major sedation could only provide minor relief.

Over the past decade my husband and I have waged a personal battle for our children to lead as normal life as possible one day at a time, and that is of course is why I'm here today.

But we are plagued by a future which presently holds neither a specific prognosis nor a cure. Our hopes exist in the research of Dr. Roscoe Brady, who is a neuroscientist and Branch Chief of the Developmental and Metabolic Neurology Branch at NINCDS.

Gaucher's disease is an inherited disorder caused by faulty enzyme activity which creates a buildup of fatty compounds called lipids within the body's cells. These accumulated substances can result in a variety of potentially life-threatening problems, most notably, the enlarged spleen and liver, lost and damaged nerve cells, the severe bone pain or bone degeneration, and reduced numbers of platelets and white blood cells.

Some forms of the disorder are terminal by age 2 and may exhibit severe nervous system involvement with a shortened life expectancy.

Gaucher's disease is 1 of nearly 200 genetic diseases related to a known enzymatic defect and it's the most common of 14 known lipid disorders. Only 1 in 40,000 may be affected in the general population, while the incidence among Ashkenazi Jews is suspected to be as high as 1 birth in every 225. So there are an estimated 20,000 cases in this country.

Through Dr. Brady's work Gaucher's has become the prototype research leading to the cure for these 14 other metabolic disorders: Fabry's, Tay-Sachs, Niemann-Pick, Metachromatic Leukodystrophy, and Faber's disease.

And because of his work, Dr. Brady's been twice nominated for the Nobel Prize and last February he was awarded the Albert Lasker Clinical Medical Research Award which you just heard about.

Gaucher's disease focuses in two areas: enzyme replacement and gene-replacement therapy and repair. Pure enzyme is extracted from placentas and it's injected to a mere 12 patients with some positive result. Adam and Laura are two of these patients.

But the scientists must learn to better direct these enzymes to sites in the body where the excessive lipids are stored.

The cost of this enzyme is exorbitantly expensive. Each injection costs several thousands of dollars. Adam and Laura are injected monthly, but the cost of the application, understanding and improving the use of this enzyme exceeds that cost of production tenfold.

Dr. Brady's team has recorded medical data on over 300 cases of Gaucher's and through the thorough study of patients who are brought to NINCDS for clinical investigation, new manifestations such as shortness of stature, partial immune deficiencies, and elevated triglyceride levels have been identified in the past year alone.

But it is imperative that patients who participate in their own free will in these programs receive proper follow-up supervision and in some instances care. Budget allocations to these clinical programs must parallel the significance of these findings.

Funds must be available to continue the study of both the conventional therapies as well as the novel approaches of enzyme replacement and gene replacement and repair. The doctors who have worked on this clinical service who are also skilled in the research practicum have demonstrated an outstanding commitment to the study of this disorder despite ever-increasing job insecurity and academic and governmental restrictions of a public medical institution.

The jobs of these professionals, along with supporting laboratory technicians, appear to be in jeopardy due to the scarcity of permanent positions and funding.

The addition of a molecular geneticist and technician to Dr. Brady's team could eventually lead to less costly production of this enzyme because utilizing recombinant DNA techniques, scientists would be able to employ bacteria to produce the large quantities of enzymes required and these engineered enzymes would have the additional advantage of being more efficient because they could be targeted directly for specific storage cell techniques.

Last, though the attention to the Institute's extramural program is commendable, emphasis on intramural programs is critical to the understanding and treatment of developmental and enzyme disorders in children.

It is of major concern that only a relatively small percentage of these funds will be dedicated to the research and clinical programs within the Institute at Bethesda, because these are the very basic programs which hold the key to Adam and Laura's future.

Please understand that my reasons for coming today are to help you understand the consequences of these financial decisions in human terms. My children's future as well as thousands of others is dependent on team effort, the right scientists with the proper information and training, and the appropriate position at a precise time.

The Gaucher's team under Dr. Brady's direction is cohesive, it's finely honed and it's moving consistently toward its goals, and they have dealt with their patients in a professional and forthright manner that has encouraged us to continue our participation.

With your help we can continue to be realistically hopeful.

Senator WEICKER. Louise, thank you very much for your very eloquent testimony.

Ms. GLICKMAN. Thank you for giving me the time. I'm sorry I took a little bit extra.

Senator WEICKER. Well, thank you. That's all right.

My problem is—I might add both professionally, I enjoy hearing about these matters which I know very little. Personally, obviously, I enjoy hearing these tales of courage, perseverance, and hope—I have my own situation there—but the only thing I want to remind everybody in the room is that everybody's got to have a chance to talk.

As I said before, I don't want to be the bad guy in this act because I know that you all have been waiting for a chance to tell your story and believe me, it's very much appreciated and I might add I'll try to come through for each one of you in the sense of what my job is.

But will you all please watch the lights here. Thank you very much.

[The statement follows:]

STATEMENT OF LOUISE S. GLICKMAN

Mr. Chairman and Members of the Committee, my name is Louise S. Glickman. I am the mother of two children, Adam, age 12, and Laura, age 8, who are affected with Gaucher's Disease, a rare enzyme deficiency being researched at the National Institute of Neurology, Communicative Disorders and Stroke.

It is a privilege for me to bring the facts about this little-known disorder to your attention by telling you their story...our story - for a chronic and debilitating illness such as theirs taxes and strains the physical and emotional fibre of each individual within the family unit. Our search for a treatment for our children is an odyssey that can be shared by anyone who has experienced severe illness first-hand.

If you have ever accompanied a child, family member or friend to a hospital for emergency treatment, then you can well understand the frustration of helplessness - something the mother of a chronically ill child feels each and every day.

By allowing me to deliver this message here today, you are helping me to help my children. You are helping them to hope that their future may be brighter for the promising research now underway at the National Institute of Neurology, Communicative Disorders and Stroke (NINCDS).

Adam and Laura are two bright and outgoing children who have the hopes and dreams of other children their age, but they are locked in the isolation of being different and the fear of an unknown future. They are small and thin with protruding bellies, due to their critically enlarged spleens. Laura has intermittent nosebleeds and both are prone to severe bruising, a constant source of embarrasment. My daughter is asked by her classmates, "Why do you look pregnant?" My son cannot participate in the sports activities so important to any young boy.

Physically tired and emotionally frustrated, their daily course is threatened by periodic bone crises which range in severity from a mild ache to pain of insurmountable intensity. Laura has been hospitalized twice with such infarcts where even major sedation could only provide minor relief.

Over the past decade, my husband and I have waged a personal battle to help our children lead as normal a life as possible - one day at a time. But we are plagued by the future which presently holds neither a specific prognosis nor a cure. Our hopes exist in the research of

Dr. Roscoe Brady, neuroscientist and Branch Chief of the Developmental and Metabolic Neurology Branch (NINCDS).

Gaucher's Disease is caused by faulty enzyme activity which creates a build-up of fatty compounds called lipids within the body's cells. These accumulated substances can result in a variety of potentially life-threatening problems - most notably, an enlarged spleen and/or liver, lost and damaged nerve cells, bone anomalies and/or degeneration and reduced numbers of platelets and white blood cells.

No two cases are alike even within the three specified types of Gaucher's Disease. Generally, Type I (Chronic or Adult form) affects bones, liver, spleen and blood but not the central nervous system. Patient's affect may range from severe to almost unnoticeable. Type II (Infantile) can be diagnosed at infancy and is terminal before age two. Almost no enzyme activity is present and psychomotor retardation is severe. Type III (Adolescent) demonstrates nervous system involvement as well as hypersplenism and bone pain. A foreshortened life span may be expected.

Gaucher's Disease, named 100 years ago by French physician Phillipe C. E. Gaucher, is one of nearly 200 genetic diseases related to a known enzymatic defect. Gaucher's is the most common of the fourteen known lipid storage disorders and yet, when Dr. Brady began his research in 1956, no one knew what caused these diseases. It took nine years for him to prove that missing enzymes were the problem; glucoceribrisidase was the missing enzyme in Gaucher's. Within two years, Brady's team identified the missing enzymes in Niemann-Pick and Fabry's disease. Tay-Sachs, perhaps the best known of these devestating metabolic disorders, is far less prevalent than Gaucher's where nearly 1 in 200 persons is a carrier. And though only 1 in 40,000 may be affected in the general population, the incidence among Ashkenazi Jews is nearly 1 in 15 as a carrier or one birth in each 225. There are approximately 20,000 cases of Gaucher's Disease in the United States alone.

Brady's group went on to produce prenatal tests for Gaucher's, Fabry's, and Niemann-Pick. In 1974, he succeeded in isolating highly purified glucoceribrisidase enzyme and injecting it into Gaucher's patients. This approach could eventually lead to the treatment of

Gaucher's in somewhat the same way diabetics are treated to overcome insulin shortage.

However, pure enzyme is presently extracted from human placentas, a tedious and costly procedure. Secondly, the research team must learn to direct the enzyme to sites in the body where excessive amounts of the harmful lipids are stored - and, in some cases, move them through the blood-brain barrier, the wall of cells that prevents large molecules from entering the nervous system.

Dr. Brady's research team has now recorded medical data on over 300 cases of Gaucher's, more than anyone else in the world, but due to funding only 12 patients have been assigned to the enzyme replacement program. Adam and Laura are two. The cost of extracting enzyme is exorbitantly expensive - with each injection costing thousands of dollars. For this reason, Adam and Laura receive their injections monthly while others receive their enzyme only bi-monthly or, as a control group, not at all. Moreover, the cost of application, understanding and improving clinical use of the enzyme exceeds cost of production at least tenfold.

By simple calculation, it is readily apparent that the expense of this research makes it prohibitive to private funding efforts. But, most importantly, Gaucher's is the prototype research for the fourteen previously mentioned lipid-storage disorders. Scientists across the country and around the world focus on Dr. Brady's work as; unlocking the cure to Gaucher's will also provide treatments of disorders like Fabry's, Tay-Sachs, Neimann-Pick, Metachromatic Leukodystrophy and Faber's Disease. Because of his outstanding discoveries and leadership in the field of lipid-storage disorders, Dr. Brady has been twice nominated for the Nobel Prize. Last February, he was awarded the prestigious Albert Lasker Clinical Medical Research Award for his excellent work.

Though much has been accomplished, there is still much to be done. Finding a treatment in Adam and Laura's lifetime is directly dependent on funding and management of personnel. In fact, Dr. Murray Goldstein, Director of NINCDS, has previously said in his testimony:

> "There are no easy ways or short cuts to foster a better understanding of the brain and its disorders, but the intramural and extramural research programs of the NINCDS are moving ahead steadily and soundly towards the achieve-

> ment of this goal through research. The ultimate resource for continued progress in neurological and communicative research is skilled research personnel."

Finding a treatment for Gaucher's Disease in Adam and Laura's lifetime is dependent on the funding and management of clinical and laboratory programs and personnel at NINCDS.

Emphasis must be given to additional study of clinical cases and funding in Gaucher's Disease. For example, new manifestations such as shortness of stature, partial immune-deficiency and elevated triglyceride levels have been identified in the past year alone through the thorough study of patients from throughout the country brought to NINCDS for clinical investigation. Budget allocations to the clinical program must parallel the significance of these new discoveries which contribute greatly to the diagnosis, treatment, and ultimate cure of the disorder.

Funds must be made available to continue the study of both conventional therapies as well as the novel approaches of enzyme replacement and gene replacement and/or repair. Doctors who have worked on the clinical service and are skilled in both the clinical and research practicum of Gaucher's Disease have demonstrated outstanding commitment to the study of this disorder, despite ever-increasing job insecurity and the academic and governmental restrictions of a public medical institution. In most instances, these are highly skilled research physicians who want to continue their work in spite of salaries far less lucrative than their counterparts in private practice.

The jobs of these dedicated professionals, along with supporting laboratory technicians, appear to be in jeopardy due to the scarcity of permanent positions and funding. Maintaining and developing research staff is critical to:

1. Provide refined methods of diagnosis and identification of carriers
2. Purify the enzyme and study its metabolism to perfect enzyme replacement therapy
3. Isolate and study the genes responsible for Gaucher's in pursuit of gene replacement therapies
4. Identify, study and treat clinical manifestations in order to better understand the disorder.

More specifically, the addition of a molecular geneticist and technician to Dr. Brady's team could eventually lead to less costly production of the needed enzyme. Utilizing recombinant DNA techniques, scientists would employ bacteria to produce the large quantities of enzymes required to treat the disorder rather than the tedious extraction method presently in use. Further, these engineered enzymes would have the additional advantage of being more amenable to specific storage-cell targeting procedures, that is, more efficient.

Lastly, the President's Revised Budget Request for FY84 of $301,554,000 would provide for 5,000 proposed project grants. Though attention to the extramural program is commendable, emphasis on intramural programs are critical to the understanding and treatment of developmental and enzyme disorders in children. It is of major concern that only a relatively small percentage of these funds will be dedicated to the research and clinical programs within the Institute at Bethesda - the very basic programs which hold the key to Adam and Laura's cure.

Please understand that my reasons for coming today are to help you understand the consequences of financial decisions in personal terms. My children's future, as well as thousands of others, is dependent on team effort - the right scientist with the proper information and training in the appropriate position at a precise time. The Gaucher's team under Dr. Brady's direction is cohesive, finely honed and moving consistently towards its goals. They have dealt with their patients in a professional and forthright manner that has encouraged us to be participating members of that team. We are realisticly hopeful.

To emphasize this point, I would like to quote from Patrick Young's article, "Biomedically, NIH Does More Better than Anyone Else" (Smithsonian Magazine, August 1979):

> "Brady has spent 25 years at NIH. His work is known worldwide; many medical schools would be delighted if he joined their faculties. But Brady prefers life at the NIH to more lucrative opportunities elsewhere, and his reasons are a measure of the place.
>
> 'My superiors are very supportive of my work', he says. 'There is a freedom here for investigation that is hard to duplicate. There is also a concentration of scientific competence...NIH is not the only place this happens, but it is a major reason I've stayed.'"

This may not be true of Brady's team members if job insecurity continues to threaten their professional lives. And then, the team which holds the key to Adam and Laura's future may no longer exist.

In closing, I would like to relate the following story to you:

Last Spring, Joann Bennett called me to say that her baby, James, had just died of Gaucher's Disease; his insurmountable ordeal of fifteen months was finally over.

Joann calls herself a "country girl" from Pearl River, Louisiana. I live in New Orleans. Our lives are worlds apart though our homes are but fifty miles away. Our companionship grew after meeting at NIH where we shared in the mutual concern of a mother for her children. Joann, like myself, sought and fought and eventually found NIH, a place where there might be an answer for her child. James, like Adam and Laura, was a part of this team effort I have referred to.

Joann Bennett kept a diary of each day of her child's illness - from the moment of diagnosis to the day of his death. She has given this diary to Dr. Brady in hopes that this will help his research. This very intense and human effort - sharing and caring between doctor and patient - is an outstanding achievement in and of itself and must be allowed to thrive and continue.

STATEMENT OF LOUISE McKNEW, DIRECTOR, WASHINGTON OFFICE, NATIONAL SPINAL CORD INJURY ASSOCIATION

Senator WEICKER. Louise McKnew, director of the Washington office of the National Spinal Cord Injury Association.

Ms. McKNEW. Thank you very much and I will talk fast.

Senator WEICKER. That's all right. Just go ahead.

I might add all statements in their entirety will be placed into the record and that doesn't mean that they get filed; I can assure you this committee and the staff read every one of them in detail.

Ms. McKNEW. Five years ago my son was paralyzed in an accident, the victim of a spinal cord injury that resulted in quadriplegia. When the doctors explained to me that a section of his cord had been so badly damaged that the message from his brain to his body couldn't get through, I suggested a solution: take a part of my cord, transplant it into his, patch him up, and send him back to school.

They said that was impossible. They said his paralysis was hopeless, forever, and permanent.

Mr. Chairman, they were wrong, and their colleagues who continue to predict permanency for newly paralyzed patients are also wrong. There is no question that my son and hundreds of thousands of similarly paralyzed Americans will walk again—the only question is when. And it is a bit of a burden but you do have power to determine when that will be.

The reason for my interest in the NINCDS budget is obvious. I've come to Congress several times over the past few years with requests for additional funding in the CNS regeneration/restoration program.

I've offered scientific, humane, medical, and motherly reasons why more money is needed. The responses have been gentle concern and sympathy, but the financial results have been minimal at best.

I've tried to figure out what I can say that will convince Congress to augment the resources we commit to cure and to come up with new information that will persuade Congress to appropriate more money especially when the squeeze is on to spend less.

First, I have to assume that perhaps Congress does not really know how close we are to a cure for paralysis. Among researchers it's common knowledge we're posed on the immediate threshold of being able to prevent paralysis from following the initial injury.

It is also acknowledged that existing paralysis will be reversed. This is not just part of a wishful future, but it's a promised relatively short-term reality.

Experimentally, transplants of nerve fibers are growing across injured sections of the spinal cord. Implanted bridges of nerve fibers are effectively bypassing the injured section of the cord. Inserted embryonic nerve cells have divided and grown down the length of the adult mammal cord.

Pharmacological substances are indeed interrupting the paralyzing process post-injury. Computerized stimulation techniques are returning atrophied muscles, weakened bones, and diminished cardiovascular capabilities back to full strength.

Biofeedbacks and technological refinements are restoring functional control to previously useless muscles. And that's just in the last 12 months.

Today experts don't question these discoveries will become clinically applicable, but they do question the wisdom of waiting.

There's a sense of urgency, born of not only the researcher's enthusiasm for pursuing a promise, but one of sensitivity to fiscal responsibility.

The rise in health care costs is front page news. Proposals to ease this burden abound including even the most unacceptable option of neglect.

But another option exists, one that offers to secure permanent gains of incalculable proportions.

Spinal cord injuries contribute to a staggering $6 billion to the annual tab for healthcare: $1,000 a day for the initial hospitalization; $15,000 a month for rehab; $10,000 a year just to get up in the morning—and I speak from experience—$6 billion for care and $16 million for cure gives us a ratio of 400 to 1. When we are so close to a cure, the investment must more closely mirror an adequate response to the opportunity researchers offer to turn care into cure.

I do suggest that new money be appropriated. The existing budget is too tight to appropriate from within, and you may want to know that there is in the administration's budget $158 million tab for nerve gas production—a controversial, questionable item in and of itself.

Personally, I think it's insane. But whose determination was it that to perfect ways to paralyze another mother's son was more important than first unparalyzing mine?

Somebody has a distorted and bizarre sense of national priority. This is still a Government of the people, by the people, and for the people, and there are half a million folks out there who would very much like to walk again.

I believe I speak for them and for their friends and families when I ask Congress to take another long, hard look at where you spend our money.

Promising theories have yet to be tested, new discoveries have not been applied, and clinical trials have been further delayed because of inadequate funds.

My son is now finishing his junior year at Yale. He's the first student ever to attend that place in a wheelchair, and I hope to God we're not back here again next year asking the same question, "When?"

Thank you.

Senator WEICKER. Great statement. Thank you very much. I also commend your son for selection of Yale.

[The statement follows:]

Statement of Louise McKnew

Mr. Chairman, honored members of this committee -- because of the request that we take no more than four minutes of your time, I will get to the point.

Five years ago my son was paralyzed in an accident, the victim of a spinal cord injury that resulted in quadriplegia. When the doctors explained to me that a section of his cord had been so badly damaged that the messages from his brain to his body couldn't get through, I innocently suggested a solution: take a part of my cord, transplant it into his, patch him up and send him back to school. With sympathy, they advised this was impossible. They said his paralysis was hopeless, forever, and permanent.

Mr. Chairman, they were wrong, and their colleagues who continue to predict permanency for newly paralyzed patients are also wrong. There is no question that my son, and hundreds of thousands of similarly paralyzed Americans will walk again -- the only question is when. And you have the power to help determine that when!

The reason for my interest in the NINCDS budget is obvious. I have come to Congress several times over the past few years with requests for increased funding in the CNS regeneration/restoration program. I have offered scientific, humane, medical and motherly reasons why more money is needed. The responses have been gentle concern, honest appreciation, and sympathy. But, the financial results have been minimal, at best. What can I say that will convince you to augment the resources committed to cure? What new information can I offer that will persuade you to appropriate more money, especially when the squeeze is on to spend less?

First, I have to assume that you don't know how really close we are to a cure for paralysis. Among researchers, it is common knowledge that we are posed on the immediate threshold of being able to prevent paralysis from following the initial injury. It is also acknowledged that existing paralysis will be reversed. What was recently considered hopeless, incurable and forever, is not just part of a wishful future, but is a promised, relatively short-term, reality. The impossible is now inevitable.

Experimentally,

- -- transplants of nerve fibres are growing across injured sections of the spinal cord;
- -- implanted bridges of nerve fibres are effectively bi-passing the injured portion of the cord;
- -- inserted embryonic nerve cells have divided and grown down the length of the adult cord;
- -- pharmacological substances are interrupting the paralyzing process immediately post-injury;
- -- computerized stimulation techniques are returning atrophied muscles, weakened bones and diminished cardio-vascular capabilities back to full strength, and
- -- bio-feedback techniques and technological refinements are restoring functional control to previously useless muscles.

All this, just in the last 12 months!

Today, experts don't even question that these discoveries will become clinically applicable. They do, however, question the wisdom of waiting. There is a sense of urgency, born of a researcher's enthusiasm for pursuing a promise, but also one born of a sensitivity to fiscal responsibility.

The rise in health care costs is front page news. The awesome burden now forced on both federal and personal budgets by medical expenses is of critical national concern. Proposals to ease this burden abound, including even the most unacceptable option of neglect.

Another option exists, however, one that offers to secure permanent gains of incalcuable proportions, and do so in the short-term.

Spinal cord injury contributes a staggering $6 billion to the nation's annual tab for health care. On a case-by-case basis, spinal cord injury is the single most expensive medical problem in the United States today. I speak from experience:

-- initial hospitalization for an acute injury totals $1,000 a day;

-- the fee for one neurosurgical procedure can reach $2,500;

-- one month in a rehabilitation hospital costs $15,000;

-- assistance just to get up in the morning costs an annual $10,000, and

-- life-time estimates to sustain one quadriplegic person total $5 million.

Six billion dollars for care, and how much for cure? All told, from both federal and private sources, we invest an estimated $16 million in the pursuit of cure. That's a ratio of 400 to 1! Why, when we are so close to a cure, can't the investment more closely mirror an adequate response to the opportunity research now offers, one that will turn care into cure?

NINCDS has budgeted $10 million for regeneration/restoration projects. The $300 million overall budget is too tight as it is -- I do not ask that existing funds be redirected from other projects. I do suggest that new money be appropriated, new money specifically targeted to cure. And I know right where you can find that money, all of it.

Mr. Chairman, do you know that the Administration's FY-84 budget includes a $158 million bill for nerve gas production? It is a controversial, questionable item, in and of itself. Personally, I think it's insane. But whose determination was it that learning how to better paralyze another mother's son was more important than first unparalyzing mine? Someone in OMB has a distorted and bizzare sense of national priority!

Senator, this is still the government of the people, by the people, and for the people. There are half-a-million Americans who would very much like to walk again. I believe I speak for them, and for their friends and families, when I ask you to take another long hard look at where you spend our money. Promising theories have yet to be tested, new discoveries have not been applied, and clinical trials have been further delayed because of inadequate funds. It makes fiscal sense, and political sense, and common sense to go for the guarantee of cure. My son is finishing his junior year at Yale, and he remains paralyzed. Will we be back next year, still asking the question, "when?"

For the National Spinal Cord Injury Association, and for myself, thank you.

STATEMENT OF DR. J. ALFRED RIDER, PRESIDENT, CHILDREN'S BRAIN DISEASES

Senator WEICKER. Dr. Alfred Rider, president of Children's Brain Diseases.

Dr. RIDER. I think I will stay within the time.

I am Dr. J. Alfred Rider, president of the board of trustees of the Children's Brain Diseases Foundation. I would like to specifically address myself to the need for continuing the support of funds for research on Batten's disease.

Our foundation has been pleased with the support of this committee in the past. In the previous Senate appropriation bills for 1981–82, the wording was used as follows:

> The committee * * * expects the Institute to expand its research on Batten's disease and related areas within the limits of high quality research available.

We feel it is extremely important for the NIH to have some strong direction into the type of research it supports. Thus, it is fitting that the final appropriations bill contain wording identical or similar to that quoted above.

Last year it was our recommendation that approximately $700,000 be set aside for research on Batten's disease by the National Institute of Neurological and Communicative Disorders and Stroke for fiscal year 1982–83. In spite of continued inflation, we would be happy to hold the line at this level for fiscal year 1983–84. We feel, however, that these funds are absolutely essential to maintain the present level of research.

Batten's disease is a neurological disorder which manifests itself in previously normal children at the approximate ages of 4 to 8 and is characterized by slow progression of clumsiness, stumbling, failure of vision, seizures, changes in personality, and dropping of scholastic grades. The disease eventually leaves them totally disabled, unable to care for themselves, and usually ends in death in the late teens or early twenties.

One of the most promising theories about the disease has resulted from the discovery of an abnormality in the peroxidase enzyme system in the brains of children with Batten's disease. This results in an accumulation of a yellow pigment called ceroid lipofuscin in the brain cells, producing slow destruction and deterioration. These changes are quite similar to the changes that take place in all brains as they age. Thus, effective treatment for Batten's disease might delay the normal aging process.

Considerable effort in the last year has been directed toward improving a blood chemistry test to identify children with the disease and their carriers. Additional studies have been done on the Kopang dogs, which have a disease similar to Batten's disease.

For example, several defective puppies have been injected intra-arterially with crystalline peroxidase. These studies have shown that the blood brain barrier can be penetrated. Of course, much additional work must be done before this technique may be utilized for humans.

Thus, we must continue to make funds available to continue with this vital research to better elucidate the pathophysiology of the disease, assist with genetic counseling, and initiate and evaluate therapy, such as feeding or injecting peroxidase and/or various antioxidants. It has been found, for example, that horseradish and avocado are high in peroxidase and are good sources of this enzyme. It is possible that pure enzyme may be obtained from the placenta or from DNA-altered bacteria.

Research is the only way to solve this disease and prevent the devastating tragedy in families who have children so afflicted and effect tremendous savings to society as a whole. The cost of care for each child is enormous and may be as high as $50,000 to $100,000 a year. Thus, 10 children such as these would cost more per year than the funds we are requesting.

Finally, the possible spinoff of enabling us to alter the aging process of senility in all humans makes the value of this research unlimited.

In the last year, research has expanded and is progressing rapidly. This momentum must be maintained. For example, we are in the process of assisting with the development of two Batten's disease centers, one at the University of Indiana and one at the University of Florida.

Because of the constraint of time, I cannot review the research studies underway, but I have enclosed them in the prepared addendum.

Suffice it to say that there are now over 34 principal investigators from major universities, medical centers, and institutes throughout the world involved in various phases of research pertaining to Batten's disease. If funding is provided, the chances of the development of a specific treatment program in the foreseeable future appear to be very good.

Thank you.

Senator WEICKER. Dr. Rider, thank you very much for your testimony. I appreciate it. Thank you.

[The statement follows:]

STATEMENT OF DR. J. ALFRED RIDER

I am Doctor J. Alfred Rider, President of the Board of Trustees of the Children's Brain Diseases Foundation. It is a pleasure to testify before the Senate Appropriations Subcommittee on Labor-Health and Human Services, Education and Related Agencies and support the budget requests of the National Institute of Neurological and Communicative Disorders and Stroke.

I would like to specifically address myself to the need for continuing the support of funds for research on Batten's disease. Our Foundation has been pleased with the support of this committee in the past. In the previous Senate Appropriations Bills for 1981-1982, the wording used was as follows: "The Committee... expects the Institute to expand its research on Batten's disease and related areas within the limits of high quality research available." We feel it is extremely important for the N. I. H. to have some strong direction into the type of research it supports. Thus, it is fitting that the final appropriations bill contain wording identical or similar to that quoted above.

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It has only been in the last 15 years that an impetus for research on Batten's disease has occurred; largely, as a result of monies from the Children's Brain Diseases Foundation and in the last four years by increased appropriations to and from the N. I. H.

Batten's disease is a neurological disorder which manifests itself in previously normal children at the approximate ages of 4 to 8 and is characterized by a slow progression of clumsiness, stumbling, failure of vision, seizures, changes in personality and dropping of scholastic grades. The disease eventually leaves them totally disabled and unable to care for themselves and usually ends in death in the late teens or early twenties.

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Thus, we must continue to make funds available to continue with this vital research to better elucidate the pathophysiology of the disease, assist with genetic counseling, and initiate and evaluate therapy; such as, feeding or injecting peroxidase and/or various anti-oxidants. It has been found, for example, that horseradish and avacado are high in peroxidase. It is possible that pure enzyme may be obtained from the placenta or from DNA altered bacteria.

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ADDENDUM

Scientists Actively Working in Research on Batten's disease

1. Doctor Donald Armstrong
   University of Florida, Department of Opthamology
   Relationships of Peroxidase to Batten's disease
   Canine Retinal Degeneration: An Approach to Therapy
   Peroxidase Deficiency & Peroxidase Regulating Enzymes
   Peroxidase Activity in Human and Canine Ceroid-lipofuscinosis, with Special Emphasis on the Eye

2. Doctor Robert J. Baumann
   Department of Neurology
   University of Kentucky & Section on Epidemiology OBE,
   Office of the Director, N.I.N.C.D.S., Bethesda, Maryland
   Leukocyte Ultrastructure

3. Doctor Milton Brightman
   Lab. of Neuropathology & Neuroanatomical Sciences
   N. I. N.C.S. & National Institutes of Public Health/
   Department of Health and Human Services
   Transport of Horseradish Peroxidase Across Blood Brain Barrier

4. Doctor Glyn Dawson
   Associate Professor, Depts. of Pediatrics and Biochemistry
   The University of Chicago
   Pre-Natal Diagnosis and Enzyme Replacement Therapy
   Approaches to the Detection of Neuronal Ceroid Lipofuscinosis in Cultured Skin Fibroblasts

5. Doctor T. L. Dormandy
   Whittington Hospital, London
   Free Radicals and Lipopigments

6. Doctor Edward Dratz
Associate Professor of Chemistry & Biochemistry
University of California, Santa Cruz
Measurement of Fluorescent Lipopigment, Peroxidized Fatty Acids, Vitamin E, Effects of Antioxidants on Lipopigment Formation

7. Doctor Paul Glees
University of Cambridge, Anatomy School, Cambridge
Electron Microscopic Studies on Neural Lipofuscin: Accumulation and Removal
The effects of Centrophenoxine in the Central Nervous System

8. Doctor H. H. Goebel
Division of Neuropathology, University of Gottingen
The Ultrastructural Spectrum and Diversity of Lipopigments in the Neuronal Ceroid-Lipofuscinosis

9. Doctor John M. C. Gutteridge
Division of Antibiotics, National Institute for Biological Standards and Control, Holly Hill, Hampstead, London
Fluorescent Products of Phospholipid Peroxidation: Formation and Inhibition in Model Systems

10. Doctor Egill Hansen
Department of Opthalmology, Rikshopitalet, The National Hospital, University of Oslo, Norway
The Significance of Psychophysical and Electrophysical Methods in the Diagnosis of Juvenile Neuronal Ceroid-Lipofuscinosis

11. Doctor Ann Harden
Department of Clinical Neurophysiology, The Hospital for Sick Children, London
Neurophysiological Studies in Children With so-called Neuronal Ceroid Lipofuscinosis

12. Doctor Denham Harman
The University of Nebraska Medical Center
Brain Lipid Composition

13. Doctor K. U. Ingold
Associate Director, National Research Council of Canada Division of Chemistry
Resistance to Oxidation and the Natural Antioxidant Levels in Membranes from Human Cells

14. Doctor Gunde Egeskov Jensen
The Laboratory of Biochemistry and Toxicology, The Institute of Biology and Chemistry, University of Roskilde, Denmark
Glutathione Peroxidase Activity in Leucocytes, Erythrocytes and Serum from Juvenile Form of Neuronal Ceroid Lipofuscinosis

15. Doctor R. D. Jolly
Department of Veterinary Pathology and Public Health, Massey University, Palmerston North, New Zealand
Ceroid-Lipofuscinosis: The Ovine Model

16. Doctor Edwin Kolodny
Associate Director, Eunice Kennedy Shriver Center for Mental Retardation, Inc., Waltham, Massachusetts
Pathogensis of the Neuronal Ceroid-Lipofuscinosis

17. Doctor Nils Koppang
Veterinaerinstuttet, Oslo, Norway
Histochemical Evidence of Lipid Peroxidation in Canine Ceroid Lipofuscinosis

18. Doctor Martin M. Maltempo
    Assistant Professor of Physics, University of Colorado Medical Center
    Monitoring of Peroxidase and Free Radicals in Canine Retinal Tissue Subject to a Degenerative Disease in Which There is an Accumulation of Pathologic Lipopigments of the Ceroid Type: A Model for Batten's disease

19. Doctor Jaime Miquel
    NASA, Ames Research Center, Moffett Field, CA
    Analysis of Pigment Lipofuscin

20. Doctor Erling Gronvold Olsen
    University Eye Department,Rikshospitalet, University of Oslo, Norway
    Fluorescein Angiography in Ceroid Lipofuscinosis

21. Doctor Vimal Patel
    Assistant Professor of Pathology
    Indiana University School of Medicine
    Antioxidant Treatment of Batten's Disease

22. Doctor Alan K. Percy
    Associate Dean, Office of Research, Charles R. Drew Postgraduate Medical School, Los Angeles
    Salutory Effect of Selenium, Erythrocyte Glutathione Peroxidase

23. Doctor Michel Philippart
    Neuropsychiatric Institute, University of California, Los Angeles
    Treatment of Batten's disease with Antioxidants

24. Doctor Mark Poznansky
    Associate Professor of Pathology, University of Alberta
    Enzyme Replacement and Enzyme Engineering

25. Doctor Raju Pullarkat
    New York State Institute for Basic Research in Mental Retardation
    Lipopigments in Aging and in Ceroid-Lipofuscinosis
    Docosahexaenoic Acid Levels in Brains of Various Forms of Ceroid-Lipofuscinosis

26. Doctor Julius Schultz
    Director, Pananicolaou Cancer Research Institute
    Miami, Florida
    Discovery and Characteristics of Leukocyte Peroxidase and the Purification and Administration to Animals

27. Doctor Gunther Schwendemann
    Division of Neuropathology, University Hospital, Eppendorf, Hamburg
    Diagnosis of Juvenile Ceroid-Lipofuscinosis by Electron Microscopy of Lymphocytes and of Rectal, Skin and Sural Nerve Biopsy Tissue

28. Doctor Aristotle Siakotos
    Professor of Pathology, Indiana University Medical Center
    Development of a Reliable Blood Test for Batten's disease
    Recent Developments in the Isolation and Properties of Autofluorescent Lipopigments

29. Doctor P. E. Spoerri
    Department of Histology and Neuroanatomy, University of Gottingen, Gottingen
    Ultrastructural Age Changes in Neurons and Myocardium in Culture. The effects of Centrophenoxine on Age Pigment.

30. Doctor Satish Srivastava
    Department of Human Biological Chemistry & Genetics
    The University of Texas Medical Branch
    Purification and Properties of Leukocyte Peroxidase
    Biochemical Studies in Neuronal Ceroid-Lipofuscinosis

31. Doctor Al Tappel
    Division of Food Science & Technology, University of California, Davis
    Properties and Functions of Flutathione Peroxidase and Pentane Analysis of Lipid Peroxidation Damage to Quantitate Effects in Nutrition

32. Doctor T. Westermarck
    Rinnekoti Institution for the Mentally Retarded, Espoo, Institute of Radiation Protection, Helsinki, Finland
    Sodium Selenite Absorption and Losses in Spielmeyer-Sjogren Type of Neuronal Ceroid Lipofuscinosis (Batten's disease) Using Total Body Counting for ^{75}Se Detection
    Studies on the Effects of Selenium Administration to Neuronal Ceroid Lipofuscinosis Patients with Special Reference to Reduced Glutathione

33. Doctor John R. Wherrett
    Professor of Neurology Program, University of Toronto
    Isolation of Fluorescent Material in the Juvenile Form of Batten's disease

34. Doctor Leon Wolfe
    Hopital Neurologique de Montreal, Montreal Neurological Hospital, Canada
    Characterization of the Accumulated Retinol Compounds in Batten's disease
    An Analysis of Urine Sediment in Subjects with Batten's disease

STATEMENT OF RAYMOND A. CONNORS, PRESIDENT, TUBEROUS SCLEROSIS ASSOCIATION OF AMERICA

Senator WEICKER. All right, now we have Raymond Connors, president of the Tuberous Sclerosis Association of America.

Mr. Connors.

Mr. CONNORS. Thank you, Mr. Chairman.

Senator WEICKER. So what you are all going to have to do is time yourself, and when you see me pick this up, you will know you are sort of coming toward the end of your time.

Mr. CONNORS. Thank you, Mr. Chairman. I ask that you include our statement as submitted to this committee into the record, and we hope all the committee members will read it. I just heard you say that for sure they would.

This is only our second time before this committee, Mr. Chairman, so anything I say here is not generally applicable to this committee.

It is not intended to attack any specific agency, committee or branch of our Government. Rather, it is just simply some observations on how our tax dollars are spent.

We understand that the requested budget for HHS is $288.4 billion and that this is probably the third largest budget in the world, next to the overall U.S. Government budget and the Soviet Union's budget.

NIH has a budget of $4 billion plus, and NINCDS only has a budget of $301,554,000—very, very inadequate, in our opinion.

In this budget, nowhere has any money ever been set aside for tuberous sclerosis. So in our statement to this committee we have asked specifically to have a minimum of $500 set aside by the NINCDS, which is approximately 1/600th of their budget, to start some research initiatives on tuberous sclerosis.

Senator WEICKER. I think you mean $500,000.

Mr. CONNORS. Yes; a half a million.

Senator WEICKER. I understand what you meant.

Mr. CONNORS. What did I say?

Senator WEICKER. $500.

Mr. CONNORS. Oh, $500,000, I am sorry. I am trying to get everything I can in in 4 minutes.

Senator WEICKER. That is all right. Now just take your time.

Mr. CONNORS. OK.

Senator WEICKER. Nobody is rushing you.

Mr. CONNORS. We make this request, Senator, because for the past 5 years in coming down here, to NINCDS and other agencies within our Federal Government, about all we have to show for it is this fact sheet that we can put our fingers on.

It is a plus, but it is not enough. When we go to NINCDS, which we firmly support by the way—and I want to repeat again this is not an attack on any agency, but just an observation of what we have encountered and how we look at the general situation on how our tax dollars are spent.

We also have—I should correct that—we also have a report on the state of the science of tuberous sclerosis, which the Congress of the United States directed NINCDS to do for us and was completed in January 1982.

We feel that the $500,000 that we are requesting is very conservative and reasonable, and we also feel that if the money is not designated by the Congress and appropriated by the Congress through this process, that there will be no research done on tuberous sclerosis, because when we have gone to NINCDS in the past, while they are very courteous to us and cooperative and try to do what they can to help us, they just don't have the money. It is that simple.

As a TS parent and a member of the American taxpaying community, I would like to make the following observations. Now, these, in some sense, do not relate at all to NINCDS, NIH, HHS perhaps, whatever.

But just as a parent of a child who is severely afflicted, 19½ years old, slowly degenerating—I use the phrase "melting away in front of my eyes"—I can't help, and many members in our organization, many members on our board of directors, reflecting upon how our tax dollars are spent.

For example—and I am not, we are not against any of these programs, by the way, but these are just observations again—$2 million for a spacesuit; $100 million for a telecommunications satellite that was a dud.

Foreign aid—if we use that term for the Third World people—I understand is in the area of $8 billion. The World Bank needs money; the IMF needs money; NATO needs money; the United Nations needs money; Egypt needs money; Central America needs money; Brazil, Argentina, Mexico, the Philippines, South Korea.

We are paying for that with our tax dollars, and yet not 1 cent for tuberous sclerosis. To us, as parents, watching our children suffer and die, it just doesn't make sense, Senator.

And this list goes on and on.

We feel that we need to sort of just point out to this committee that maybe it is time to take a little inventory of our priorities, and maybe it is about time we started thinking a little bit the way the oldtimers used to think, "charity begins at home" here.

We are playing Santa Claus to the rest of the world while our kids are literally dying, and there is not 1 cent for tuberous sclerosis. In our case, no clinics, no hospitals specializing in this disease. There are none for tuberous sclerosis.

Treatment for these children is hit or miss at best; "scattered at random," one doctor described it to me. Quite frankly, we feel that this is wrong.

I think in our last testimony we explained some of the symptoms of tuberous sclerosis. It causes mental retardation, epilepsy. It affects the calcium in the body.

And in the case of my son his teeth are literally rotting out of his head from the inside out. His legs never really developed; they are like sticks. A profile of him looks like a letter Z. He has severe scoliosis. If nothing else kills him, that will.

And if he were the only case, I would say, "OK, it is my problem, I will live with it," but there are thousands of other kids like this in homes, some in institutions.

Now, the thing is that in a case like my son, for example, he may be suffering from impacted teeth, et cetera, et cetera, packed inside of his jawbones. The drug he is on is dilantin. It causes gum tissue growth. He is a drug addict. To use a phrase, he is a basket of seizures, Senator. He is mentally retarded, and he has no speech. He can't vote. He is old enough to, but he can't vote. He can't even, you know, feed himself. He doesn't even know how to spit.

And I am watching my tax dollars go out on all these programs, none of which I am really opposed to; I just feel that the priorities are a little out of whack, and so do the members on our board of directors and members of our organization.

And so, sir, we would like to ask this committee—as far as we know, you supported us last year—we ask that you support us again this year and do what you can to get an increase for the NINCDS budget.

Senator WEICKER. Well, let me say this. I think you have very eloquent testimony there, Mr. Connors, and I can assure you we will take a careful look at your request. I would like to have that fact sheet if I could.

Mr. CONNORS. Yes, sir.

Senator WEICKER. I think you state your case very well.

Mr. CONNORS. Thank you, sir.

Senator WEICKER. Thank you very much.

Mr. CONNORS. Thank you very much.

[The statement follows:]

STATEMENT OF RAYMOND A. CONNORS

My name is Raymond A. Connors, a Founding Director and President of the Tuberous Sclerosis Association of America, Inc. (TSAA), and the father of a child severely afflicted with tuberous sclerosis (TS).

We are happy to be here today and thank you for the opportunity to be heard. On May 3, 1982, the TSAA appeared before this Committee for the first time and submitted a brief history of tuberous sclerosis and the TSAA. Specifically outlined proposals directed toward tuberous sclerosis research were included in our text with a request that NIH/NINCDS implement same.

The attached letter from Dr. Murray Goldstein, Director, NINCDS, dated February 17, 1983, suggests that marginal consideration has been given to some of our recommendations. We feel that the continued support of this Committee is most essential to ensure that planned NINCDS initiatives do not flag and additional action is taken.

At this time, therefore, we re-submit our recommendations for your consideration and review, as follows:

That a National Consensus Conference be called, sponsored by NINCDS, to address the following issues:

(a) the identification of all diagnostic criteria extant in TS;

(b) the pooling of current knowledge regarding treatment and health maintenance for TS patients;

(c) the cataloging of needs vs available community supports for TS families;

(d) the development of a literature for professional and lay audiences to enhance sensitivity to this common disease;

(e) the organization of a national TS registry.

Second, that specific and categoric issues be identified that have never been addressed by the scientific community, issues in urgent need of investigation, including an analysis of how the seizures (epilepsy) of TS patients are different from the general population of epileptics with whom they are often confused. The establishment of early treatment protocols for those identified as having TS at birth and the effects of such treatment on cognitive and behavioral development, as well as continuation of the specific laboratory-based neuro-genetics research looking into the molecular biology and chemistry of the TS individual as addressed in the NIH Report on Tuberous Sclerosis of January, 1982. That Congress express to NIH its awareness that TS research must cross many present programmatic boundaries, including activities in neurogenetics research at NINCDS, programs being promoted by Maternal and Child Health and other categoric activities under the National Institute of Child Health and Human Development and Mental Retardation.

That the NINCDS encourage extramural scientific initiatives for the study of TS-related concerns through announcements in the regularly published NIH Guide for Grants and Contracts.

We respectfully request that this Association (TSAA), when appropriate, be an active participant of any effort(s) initiated by this Committee on behalf of tuberous sclerosis.

A positive statement by this Committee, similar to that found in last year's House Report No. 97-894, Sept. 29, 1982 (Appropriations Bill for the Departments of Labor, HHS & Education), would be very helpful in carrying out these recommendations.

> "The Committee encourages the Institute to begin to address issues such as the identification of all extant diagnostic criteria for tuberous sclerosis; the pooling of current knowledge regarding treatment and health maintenance for TS patients; the cataloging of needs and available community supports for TS families; the development of a literature for professional and lay audiences to enhance sensitivity to this common disease; and the organization of a national TS registry. The Committee also hopes that the Institute will encourage more research on tuberous sclerosis including areas which have not yet been addressed."

Since no specific funds have ever been set aside for research on tuberous sclerosis, interested investigators, scientists and physicians are discouraged from submitting grant proposals. TS should not be lumped with other diseases and disorders such as the phacomatoses, mental retardation, epilepsy, cancer, etc., etc., nor forced to compete for funding with other such maladies. Tuberous sclerosis needs and requires its own research programs.

In order to ensure that our recommendations will be funded, we ask, initially, that Congress direct the NIH/NINCDS to set aside $500,000 in FY'83-84 for tuberous sclerosis research. $500,000 represents less than 1/600th of the total NINCDS budget of $301,554,000. In relation to the total HHS budget of $288.4 billion, $500,000 is approximately 1/577,000th.

Tuberous sclerosis is one of the most common genetic disorders that devastates our children and the family unit. Throughout the United States thousands of TS families pay their fair share of taxes to the federal government. In view of the vast sums of tax dollars that are spent by federal agencies such as HHS/NIH/NINCDS to fund research programs, we feel that our request for tuberous sclerosis is most conservative. Further, when one considers it costs $500,000 (at a rate of approximately $50,000 per year) to maintain one individual in an institution for 10 years, this is a very small sum. This, of course, does not even begin to address the catastrophic medical costs incurred by TS families at home.

As a population, the needs of TS children and their families have been grossly neglected. Nothing of any consequence has ever been done for this disease or these families. The time for talking is past and the time for action is long overdue!

Daily inquiries bring ever-increasing numbers of TS victims to our attention which certainly supports the belief of many physicians that TS is far more common than anyone ever suspected and that improved diagnostic techniques, along with escalating educational programs, will continue to demonstrate this fact.

Tuberous sclerosis is too common and complex an illness to be consigned as part of broad-based scientific research that involves myriad other genetic diseases and disorders, some of which are not medically related. We feel it would be like putting flu and cancer in the same research program. In the past, some limited research has occurred as a result of studies piggy-backed on other research programs. Needless to say, no results of any import have come out of this very limited research. Because of its complexity and the multi-disciplines involved in the care and treatment of TS victims, meaningful research requires a program specifically directed to tuberous sclerosis and should involve a team of physicians and scientific research investigators for maximum results.

Tuberous sclerosis is a genetic disease with neurological involvement, first identified more than 100 years ago. Despite its long medical history, TS remains little known, poorly understood and frequently misdiagnosed.

The incidence of TS is thought to be 1:5,000--1:10,000 in the general population. TS is as common as many better known diseases such as Cystic Fibrosis (1:6,000), and ten to twenty times more common than Duchenne's Muscular Dystrophy (1:100,000).

TS symptoms range from mild to extremely severe and may manifest at various stages of the afflicted child's development. In its severe form, tuberous sclerosis can be very devastating, making the victim completely helpless and dependent.

It affects both males and females and may occur in any race. The disease is generally characterized by one or more of the following conditions: epilepsy, mental retardation, hyperactivity, tumors, physical handicaps, developmental delay, behavior problems, learning disabilities, characteristic skin rash and white skin spots.

In preparing this statement, all involved were cognizant of the FY'84 funding level(s) proposed for NIH, as well as NINCDS, which we fully support. We wish it could be doubled, even quadrupled! Funding levels for new research initiatives should be adequately provided for in the budget. However, as our testimony indicates, regardless of funding levels, we feel these agencies must provide funds for tuberous sclerosis research.

For the first time in the history of mankind, we have the technology, the opportunity, and the skill necessary to research and even conquer many diseases that were previously unapproachable and continue to undermine our society and destroy the family unit. The young, the infirm, the afflicted and voiceless masses of many of our people should have to wait no longer for a spark of hope and promise of respite from the maladies that afflict them.

We join with this Committee and other agencies throughout the country in making it abundantly clear to the present and future Administrations that we, as a people, insist that an even greater and more appropriate portion of our tax dollars be allocated to the health and well being of our less fortunate loved ones.

In closing, I would again like to thank this Committee for the opportunity to discuss what we consider a most urgent concern. I would be happy to answer any questions you might have.

SUMMARY

The following recommendations are requested by the Tuberous Sclerosis Assn. of America (TSAA) to add to present NIH activities being conducted under the aegis of NINCDS:

1. That a National Consensus Conference be called to codify present available information regarding TS diagnosis and treatment;

2. That specific and categoric areas for scientific research be identified that have never been addressed by the scientific community rather than allow TS to be placed with other syndromes;

3. That Congress express to NIH its awareness that TS research must cross present programmatic boundaries;

4. That NINCDS encourage extramural scientific initiatives for the study of TS through announcements in the regularly published NIH Guide for Grants and Contracts;

5. That a minimum of $500,000 be set aside for research on tuberous sclerosis by the National Institute of Neurological & Communicative Disorders and Stroke for FY 1983-84;

6. That the Tuberous Sclerosis Assn. of America (TSAA), when appropriate, be an active participant of any effort(s) initiated by this Committee on behalf of tuberous sclerosis.

February 17, 1983

Raymond A. Connors
President
Tuberous Sclerosis Association
  of America, Inc.
P.O. Box 44
Rockland, Massachusetts 02370

Dear ~~Mr. Connors~~ Ray:

It is my firm intent that the National Institute of Neurological and Communicative Disorders and Stroke (NINCDS) will work together with the Tuberous Sclerosis Association of America, Inc. (TSAA) to address the research challenges which tuberous sclerosis presents to the neurological community. As you know, the legislative authority of the NINCDS is limited to research; the Institute does not have authority for programs of patient care or community services. A copy of Dr. Joseph S. Drage's response to Dr. Thomas B. Fitzpatrick's comments on the Report on Tuberous Sclerosis is attached.

In your earlier letter and in our telephone conversation, we discussed the desirability of a research workshop on scientific issues relevant to tuberous sclerosis. Dr. Drage has sent you the research conference grant application forms and instructions. It is my understanding that Dr. Fredrick Bowman will be preparing this application and will be in contact with Dr. Drage.

In order to emphasize to the biomedical research community the NINCDS interest in research on the phacomatoses, the Developmental Neurology Branch is preparing a program announcement requesting the submission of research grant applications on the phacomatoses, including tuberous sclerosis. This program announcement will encourage the submission of research grant applications in relevant basic science areas as well as in clinical research areas such as epidemiology, diagnosis, treatment, and prevention.

The NINCDS staff recommends that a tuberous sclerosis registry is most appropriately established and maintained by the TSAA, with the TSAA determining access to the registry by investigators. If you wish, NINCDS staff will advise and counsel the TSAA in the development of the registry.

The NINCDS also will plan to consult with the TSAA in reviewing existing NINCDS literature and will be happy to work with TSAA in planning for new literature.

I hope that you maintain close contact with Dr. Drage. As Chief of the Developmental Neurology Branch of the Convulsive, Developmental, and Neuromuscular Disorders Program, he is the person most knowledgeable about development of the NINCDS research program relevant to tuberous sclerosis.

With best regards.

Sincerely yours,

Murray

Murray Goldstein, D.O., M.P.H.
Director
National Institute of Neurological and
Communicative Disorders and Stroke

STATEMENT OF NANCY MACE, ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION

Senator WEICKER. The next witness is Nancy Mace, for the Alzheimer's Disease and Related Disorders Association.

Ms. MACE. I am here on behalf of the Alzheimer's Disease and Related Disorders Association.

Ours is a national organization made up of about 68 chapters now—it is only about 3 years old—as well as 300 family support groups across the country.

By way of background, I am a member of the T. Rowe and Eleanor Price Teaching Service, a team of people at Johns Hopkins University who are providing care to people who are suffering from Alzheimer's disease and to their families.

I recently wrote a book titled "The 36-Hour Day," which is intended to serve as a guide for families of people suffering from these dementing illnesses. I have provided your staff with a copy of the book.

[CLERK'S NOTE.—The book is in the subcommittee's files.]

Senator WEICKER. Thank you very much.

Ms. MACE. Mr. Chairman, contrary to what most people believe, loss of memory or intellectual ability is not a normal consequence of aging. It is most often caused by Alzheimer's disease, which afflicts about 1½ million elderly and about 60,000 middle-aged adults. As a matter of fact, we occasionally see cases where the disease has stricken individuals in their twenties.

Research has demonstrated that Alzheimer's disease is a neurological disorder. It is not clear yet just what causes the disease. We do know that it attacks the brain and damages the nerve cells which transmit messages within the brain. What results is prolonged misery for the victim and a great deal of emotional suffering for his family.

Certainly no disease is bearable, but I can assure you Alzheimer's disease is merciless. At first, the individual with the disease experiences only minor symptoms of forgetfulness and some confusion, and he usually knows what is happening to him. As the disease progresses, it produces severe memory loss and drastic changes in his behavior. In time, individuals with Alzheimer's become totally incapable of caring for themselves.

Alzheimer's is a fatal disease from which people suffer for a variable period, which ranges now up to about 15 years. As you know, half of the admissions to this country's nursing homes are persons suffering from an Alzheimer's-like disease, which leads me to why I am here today.

This disease causes enormous pain and anguish, beginning with the individual who senses that he is losing his intellect. Beyond that lies severe emotional and financial strain for families.

Alzheimer's disease is not usually covered by medicare or by most private insurance plans. Alzheimer's victims require round-the-clock supervision and assistance for most of the years of their illness. Thus families must bear the cost of caring for them.

Contrary to what some people believe, about two-thirds of these people are cared for at home by their families at enormous cost.

It is difficult to measure all of this in terms of dollars. We do know that Alzheimer's-like diseases cost more than $11 billion annually for the one-third of those people who are in nursing homes. Billions more are lost as a result of medical expenses and wage and productivity losses.

Our only hope for finding the cause and treatment of Alzheimer's disease lies in research. Rapid strides are being made. We are seeing new breakthroughs regularly.

Much of what we have been able to learn about the disease has stemmed from research supported by the National Institutes of Health and the National Institute of Mental Health.

I know that this subcommittee faces a lot of difficult issues this year. I know, too, of its strong support for biomedical research.

I urge you to provide the funds necessary for a continued strong research effort in this area. You know that only a sustained effort will attract the talented researchers that we now think can get to the bottom of this disease.

Our association is recommending appropriations of $330 million for the National Institute of Neurological and Communicative Disorders and Stroke, and $110 million for the Aging Institute.

Thank you.

Senator WEICKER. Your statement will be included at this point in the record, as well as other statements submitted for the record on fiscal year 1984 appropriations for the National Institute of Neurological and Communicative Disorders and Stroke.

[The statements follow:]

STATEMENT OF NANCY MACE

My name is Nancy Mace and I am here on behalf of the Alzheimer's Disease and Related Disorders Association.

Ours is a national organization made up of 68 chapters, as well as 300 family support groups across the country.

By way of background, I am part of the T. Rowe and Eleanor Price Teaching Service -- a team of people at The Johns Hopkins University who provide care to individuals suffering from Alzheimer's disease. Not long ago, I wrote a book entitled "The 36-Hour Day," that is intended to serve as a practical guide for families of people with dementing illness. I have provided staff with a copy of the book.

Mr. Chairman, contrary to what many people believe, loss of memory or intellectual ability is not a normal consequence of aging. It is most often caused by Alzheimer's disease, which afflicts 1.5 million elderly and about 60,000 middle-aged adults. As a matter of fact, we have seen cases where the disease has striken individuals who are still in their twenties.

Research has demonstrated that Alzheimer's disease is a neurological disorder. It is not clear just what causes the disease. We do know that it attacks the brain and damages the nerve cells which transmit messages in the brain. What results is prolonged misery for the victim and a great deal of emotional suffering for family and loved ones.

Mr. Chairman, certainly no disease is bearable -- but I can assure you, Alzheimer's disease is merciless. At first, the individual with the disease experiences only minor symptoms, usually forgetfulness and some confusion. As the disease progresses, it produces severe memory loss and drastic changes in behavior. In time, individuals with Alzheimer's become totally incapable of caring for themselves. Alzheimer's is a fatal disease from which people suffer for a variable period ranging up to 15 years. As you perhaps know, half of the admissions in this country's nursing homes are persons suffering from Alzheimer's-like disease.

Which leads me to why I am here today.

Mr. Chairman, this disease causes enormous pain and anguish, beginning with the individual who senses that he is losing his intellect. Beyond that lies severe emotional and financial strain for families. You see, Alzheimer's disease is not covered by Medicare or by most private insurance plans. Alzheimer victims require round-the-clock supervision and assistance for many years. Thus, families must bear the cost of caring for a loved one.

It is difficult to measure all of this in terms of dollars. We do know that Alzheimer's-like diseases cost more than 11 billion dollars annually for the one-third of these victims who are in nursing homes. Billions more are lost as a result of medical expenses and wage and productivity losses.

Mr. Chairman, our only hope for finding the cause and treatment of Alzheimer's disease lies in research. Rapid strides are being made. Much of what we have been able to learn about the disease has stemmed from research supported by the National Institutes of Health and the National Institute of Mental Health.

I know that this Subcommittee faces a lot of tough issues this year. I know, too, of its record of strong support for biomedical research.

I urge you to provide the funds necessary for a strong research effort in this area.

Our association is recommending appropriations of 330 million dollars for the National Institute of Neurological and Communicative Disorders and Stroke, and 110 million dollars for the Aging Institute.

Thank you, Mr. Chairman.

STATEMENT OF GUY M. MCKHANN, M.D., PROFESSOR AND CHAIRMAN, DEPARTMENT OF NEUROLOGY, JOHNS HOPKINS HOSPITAL AND MEDICAL SCHOOL

The last few years has seen amazing strides in our understanding of both the normal and abnormal nervous system. Just to name a few areas, one could point to how we now image the nervous system with such new techniques as computerized axial tomography (CAT scanning), positron emission tomography (PET scanning) and nuclear magnetic resonance (NMR). Thus we can now look at both normal and abnormal nervous systems in the awake functioning person.

At a cellular level we have learned much more about how one nerve cell talks to another. These chemicals that influence the behavior of a nerve cell are called neurotransmitters. A few years ago we knew only of five or six. Now we know about 50, 60, or even 70 such compounds.

The importance of these basic discoveries is that we can now ask questions about human disease we could not ask before. For example, we now have a much better idea about the mechanism of Alzheimer's disease. That is, the disease that leads to dementia in middle-aged and adult humans. New knowledge about neurotransmitters is now being applied to the area of spinal cord injury. Previously we felt that the spinal cord once injured could not recover. Now we have a reason to believe, based on animal experimentation, that partial injuries to the spinal cord might be quite reversible. The implication of these findings to the human require further clinical investigation.

There is great interest in the nervous system at the high school, college, graduate school and medical school levels. We are seeing large numbers of extremely well-trained, extremely bright students interested in studying the brain. We have newer techniques so that we can ask newer questions and we are getting meaningful results in relationship to diseases of the brain.

In summary then, we have the people, we have the techniques, we have the ideas, this is no time to cut in support. Rather it is a time to increase support for the application of all these plus factors so that we can learn more about both the normal and abnormal nervous system.

STATEMENT OF STANLEY VAN DEN NOORT, M.D., VICE CHAIRMAN, NATIONAL COMMITTEE FOR RESEARCH IN NEUROLOGICAL AND COMMUNICATIVE DISORDERS

Multiple Sclerosis (MS) is a chronic crippling disease which affects the brain and spinal cord and occurs primarily in young people. Research over the last 20 years has established that it is probably "autoimmune", i.e. the result of a misdirected attack by the affected person's immune system on his own nervous tissue. It appears to be initiated by common virus infections such as measles or chicken pox, in early life. It is more frequent in people with a genetically determined susceptibility, which is expressed as an inability to regulate aberrant immune reactions.

There are important targets of opportunity here. New methods have been discovered within the last two years to change immune regulation and shut off autoimmune reactions. These are being tested in mice with model diseases resembling MS and will surely be ready for testing in MS within 2-3 years. New oral vaccines and antiviral chemotherapy promise a marked reduction in childhood viral infections. New genetic markers, yet to be studied in MS offer the possibility of accurate diagnosis of early disease, as well as a more exact prognosis of its later course. These require study in carefully selected populations and in families with multiple cases of MS.

It is our belief that adequate study of patients with MS and animals with experimental diseases resembling MS from the immunologic, virologic, and genetic standpoints will ultimately lead to total elimination of this disease. Each of these three sciences has made extraordinary advances in basic concepts and technology during the 70's. Even today, new "breakthroughs" are reported almost daily, and these are being applied to diseases such as MS with great speed. To cite a single example, the production and use of monoclonal antibodies were first described in 1975 in immunologic studies of mice, were applied to investigation of human diseases within two years and to MS in three. Important new findings obtained with this powerful method had reached publication in the influential New England Journal of Medicine by 1980. Monoclonal antibodies have already been applied to treatment of human disease with exciting results.

An air of optimism pervades research on MS and similar diseases of the nervous system today. Substantial numbers of highly qualified immunologists, virologists, and geneticists have moved into the field, and the number of research projects related to MS has grown at an extraordinary rate. For this disease alone, approximately 20 grant applications of high scientific merit for "relevant" research, which were reviewed by the National MS Society's expert advisory committees in the Fall of 1982, could not be supported with available funds, and NINCDS was unable to pick up more than a few of these.

This represents a shortfall of over $1 million annually, just for the disease MS. For the larger group of MS and related diseases -- one may name other demyelinative diseases, optic neuritis, Guillain - Barre polyneuritis, chronic relapsing polyneuropathy, SSPE (subacute sclerosing panencephalitis), Sydenham's chorea, myasthenia gravis, paraneoplastic syndromes such as Eaton-Lambert syndrome, systemic lupus erythematosus affecting the nervous system, dermatomyositis, and the spongiform encephalopathies (Creutzfeldt-Jakob disease) -- the estimated shortfall would be $8 million or more. If one includes funding for immunologic, virologic, and immunogenetic research at a more basic level, a realistic figure might be $12 million over the present level of funding.

In the absence of a "cure" for such diseases as MS, a good deal of effort is expended on the study of agents which ameliorate the disease process by reducing immune reactivity or inflammation or correcting neurologic dysfunction. With several new agents, which are yet to be tested, one also entertains the possibility of a real cure. However, to establish reliably the safety and efficacy of a new agent requires costly and prolonged clinical trials (randomized, controlled, double-blind studies) in large groups of patients. A properly conducted trial of a single new agent or combination of agents in MS costs $300,000 - $500,000 today. Because of this price tag, the NIH has been unable to fund significant numbers of clinical trials, since this would divert funds from more basic research directed to full understanding (and ultimately to permanent prevention or cure).

Yet, as sophisticated knowledge of MS has become widespread, together with awareness of how proper trials should be carried out, there has been increasing pressure to fund new trials. Indeed there are more than 80 clinical trials of one or another agent or procedure in MS current at the present time in the United States and elsewhere. Some of these are based on recent scientific findings and represent radical new departures in therapy. Others are attempts to confirm and extend results of preliminary trials or empirical findings reported by others. Both approaches are, of course, essential if we are to achieve optimal management of this dreadful disease.

It is urgent that NINCDS be assigned additional funds specifically for use to support clinical trials of new drugs or procedures in MS. A reasonable figure would be $3 million annually, which would permit funding of 6-10 new starts a year. It is essential that these funds not be taken from the existing budget for more basic research. There is no question that the demand (high quality, well formulated proposals) will far exceed funding offered at this level.

One may calculate that any medical breakthrough for MS could easily save the Federal Government its investment in clinical trials many times over. If a new treatment resulted in removal of 1500 persons with MS from public income maintenance and public assistance programs and prevented another 2,000 from requiring such benefits, it would save the Government about $25 million in those programs alone during the first year. This estimate is based on the assumption that the average Government cost for one person with MS (with family in many cases) is $7,000/year for SSDI and SSI and Food Stamps or other income maintenance of public assistance programs (Federal Employees Disability Retirement, VA pensions, Railroad Retirement, AFDC, Housing Assistance, Low Income Energy Assistance, etc.)

In summary an incremental increase of the budget for NINCDS to provide $12 million for research in the immunology of multiple sclerosis and related nervous system diseases and to provide $3 million for the support of urgently needed clinical trials would provide an enormous gift of hope to our patients, a conservative investment in the pursuit of a major national problem, a certainty of high return on this investment in the years ahead. Your support and consideration of this proposal is earnestly solicited.

STATEMENT OF RUTH LEMBECK

I am writing this in lieu of being able to give Public Witness testimony to members of the Senate and House Subcommittees convening to appropriate funds for research in the National Institute of Neurological and Communicative Disorders, Stroke.

I want to tell you about what surely must be the most neglected of all orphan diseases. It has no voluntary organization to work for its victims. It has no foundation to accrue funds and disperse them for research. It has no communications network to keep those with the disease informed...no public information program to tell the world it exists and must be fought for. It boasts no special centers for its diagnosis and treatment. Last, and most deplorable of all, it has no research whatsoever being done to seek its cause and cure, no funds to support such research. Because of these lacks, it cannot even join other groups that might offer the support and focus it requires. In a sense, it is a non-disease, for it simply does not exist...except, painfully, for those who have it!

A rare, highly destructive progressive disorder of the spinal cord, it cripples and it shortens life. Its name describes it - syringomyelia - syrinx of the spinal cord.

Syringomyelia falls into no established medical category. It is neither bio-chemical nor genetic, and it is not an immune, endocrine, or metabolic problem. Ultimately, however, it becomes a major neuro-muscular disaster for those who have it. It is termed a disease, but it is actually a condition, one which can become evident as early as age 3 or as late as age 60, but is usually first manifest around the age of 30. It apparently occurs more often in males than in females. No one will hazard a guess as to how many syringomyeliacs there are in the U.S. Their numbers are undocumented.

My son has syringomyelia. The onset at age 25 was sudden. He became numb in the left foot, and within a few months, his entire left side, including his tongue, was without feeling, and he became impotent. 7½ hours of micro-surgery revealed what scans and other testing had suggested - an obstruction, a massive enlargement of the mid- and upper spinal cord, proved to be syringomyelia.

Under normal body conditions, there is a consistent flow of cerebral fluid from head to spinal cord and back again. With syringomyelia, the syrinx acts as a catchbasin, and some of that fluid cannot escape to flow freely, as it should. Eventually, the cavitation fills and becomes distended, pressing on the lining of the central canal, creating fissures within it. The fluid can then begin to dissect the inside of the cord, interrupting nerve connections, destroying neurons, creating the neurological deficit known as syringomyelia, (SM).

In general, SM symptoms are similar to those of other, better-known diseases, among these, amniotrophic lateral sclerosis (ALS or Lou Gehrig's disease), multiple sclerosis (MS), tumors of the spinal cord, cervical spondylosis (fusion of vertabrae with one another, platybasia (a developmental anomaly of the skull), and skeletal anomalies of the cervical spine.

Specifically, syringomyelia symptoms include any or many of the following: deep, boring pain...weakness/paralysis of voluntary motion... spasticity...change of gait and loss of motor abilities...atrophy of bones (they become calcified and osteoporotic)...gangrene...total loss of either pain or temperature sense (one eminent neurosurgeon told me of an SM patient who progressed to the point of no sensation anywhere in his entire body!!)...ulcerous fingers (from unfelt cuts or burns). All of these, as well as others not cited, are examples of the irreparable damage visited on the body by syringomyelia. Even when discomfort and pain have been temporarily alleviated (and this is all the medical world is able to do now - alleviate!) the disease continues on its insidious course. No way to halt it has been found because, quite simply, no search has been made.

Syringomyelia has many variables. For one thing, there are different types of the disorder. For another, its patterns are erratic and unpredictable - baffling and frustrating both to its victims and to the physicians who treat it. Because each case differs from the other, methods of treatment must be adapted or devised to fit. All treatments currently in use attempt to reestablish normal communication for the fluid between spinal cord and head, and theoretically they should work, but in practice they have many problems. Adhesions can form again, shunts can move out of place or become plugged, small openings applied by the surgeons can seal off as the cord tends to collapse, and other conditions can arise, stymieing efforts to effect any permanent cure. Gaps in knowledge and lags in communication also contribute to the confusion and the inability to help geographically-dispersed syringomyeliacs. It is thought that there are many undiagnosed cases of SM.

Cause of the disorder is still unknown. It is frequently referred to as congenital, based on the belief that when a baby is forming in utero, some glial cells go astray, wander into the spinal canal, and form a tube or cavitation (syrinx), but this is a matter of conjecture. Then, too, there is another form of syringomyelia that results from trauma - spinal cord injury sustained during military action, automobile accidents, or sports activities.

As stated earlier, no breakthrough research is in progress. The only type of research being done is the long-range, clinical tracking of patients - making note of physical changes as the disease moves on its course. This cannot possibly supply what my son and other syringomyeliacs need so desperately - a way to halt the disease in its tracks for good and aye, and as quickly as possible, for with a progressive disease, every day counts!

Jamie, my son, is now waiting for NMR (nuclear magnetic resonance) and other testing at Dent Neurological Center in Buffalo, where he lives. The microsurgery drained the syrinx, relieved the pressure and kept him symptom-free for a while, but he is numb once again - in the left foot, left hand and arm, and has 24-hour pain in the cervical area which peaks in intensity during sleeping hours. Whatever they learn from the new testing will add only to the clinical knowledge.

There are no definitive answers for Jamie's condition, and there will be none unless qualified researchers acquire monies enough to support all-out focus on syringomyelia. The likelihood of this depends wholly on whether the Senate and Congress Subcommittees appropriate enough funds to spinal cord diseases under Orphan Drug Bill authorizations to allow for breakthrough research on this disease, for as I pointed out, SM has no foundation of its own, no source of funding other than the government. Please...for the sake of my son and all other syringomyeliacs...consider all the foregoing facts with compassion and generosity when this comes up for final consideration. Thank you.

STATEMENT OF DR. OLEG JARDETZKY, DIRECTOR, STANFORD MAGNETIC RESONANCE LABORATORY, AND PRESIDENT, ASSOCIATION FOR ADVANCED TECHNOLOGY IN THE BIOMEDICAL SCIENCES

Senator WEICKER. Thank you very much. I appreciate your testimony.

We now move on to the NIH Division of Research Resources. The first witness in this regard is Dr. Oleg Jardetzky, director of the Stanford Magnetic Resonance Laboratory, and president, Association for Advanced Technology in the Biomedical Sciences.

Dr. Jardetzky.

Dr. JARDETZKY. In this day and age of personal computers and other kinds of gadgets, it would seem hardly necessary to belabor the need for advanced technology in medical science and medical practice. However, if one takes a look at the developments described in my written testimony, which I will not read, it is quite clearly necessary to point out that the introduction of advanced technology into medical science and medical practice is neither properly organized nor properly funded, and I would like to focus your attention just on three problems that exist in this area.

First of all, the instrumentation which has been accepted in medical science as part and parcel of the techniques used is subject to rapid obsolescence and because of the funding constraints on the NIH in the last 10 years it has not been replenished at the rate at which it should be.

This is a well-recognized problem. It is a persistent problem. It is probably the easiest and the simplest to tackle.

Much more serious problems exist in two other areas. First, there are technologies which have been developed in other fields that have major implications for medicine which should be applied to medical research and to medical practice, but there are no budgetary provisions at all in the NIH to introduce such technologies.

I can cite one example from the field in which I work myself, and that is the field of nuclear resonance. This technique has been used for about 25 years in chemistry and in physics to identify chemical compounds.

In the last 2 years it has become possible to build very large, very homogeneous magnets where you can put in an entire person and you can get signals from within the human body and you can study in considerable detail the chemistry, the metabolic processes that go on. It is also possible to obtain images of soft tissues of the body, something that X-rays and CAT scanning and PETT scanning cannot do.

Well, there are three places in this country where work is being done along these lines—Yale, the University of Pennsylvania, and Stanford. It is a technique of enormous potential in medicine and with enormous implications for medical diagnosis and in monitoring of therapy.

But it is a very expensive technique. We have recently made a study at Stanford as to what it would cost to really set up a human NMR center, and the cost is about $6 to $7 million per medical center, and there is no program at all in the NIH that is capable of undertaking that kind of a request.

The third problem that exists is that there are technologies which could and should be developed for medical use, and again there are no provisions for funding these technologies, and I specifically think here of things like artificial intelligence and its use in medical diagnosis, which requires expensive computer installations and a great deal of personnel support.

This is not a situation that should be allowed to persist, and we would like to recommend several remedies.

In 1981, Congress has mandated the NIH to conduct a study of instrumentation, and in 1982 the NIH has submitted a report, pointing out the unsatisfactory state of instrumentation funding and requesting an additional $5 million for the biotechnology resources program for the next 5 years—annually—and $20 million for instrumentation in general.

In fiscal 1983, the House had recommended that this be done. The Senate did not. The net addition was $12.5 million.

In 1984, this item has disappeared from the budget. Considering the new developments, this is still a drop in the bucket, and we would like to recommend, first of all, that in fiscal 1984 the $25 million add-on that has been recommended by the NIH in the 1982 report be reinstituted. And the second thing we would like to recommend is that the NIH study submitted in 1982 be updated in the light of new developments because there is clearly a need for legislation and administrative provisions within the NIH to create major technological centers, and that should become apparent in the updated report.

Thank you.

[The statement follows:]

STATEMENT OF DR. OLEG JARDETZKY

Over the past years complex and sophisticated technology has played a steadily increasing role in Medical Science and over the next years it will have an even greater impact on Medical Research and the Practice of Medicine. This development is posing a new problem for those who fund Medical Research. Traditionally, Medical Research is not accustomed to the need for such complex and costly technical installations that have now become commonplace in High Energy Physics, Engineering and Earth Sciences. The budgetary structure of the National Institutes of Health contains few provisions to fill the rapidly rising need for the development and application of sophisticated advanced instrumentation. The nature of the mission of other federal funding agencies such as the National Science Foundation and the Department of Energy precludes their dedicating their resources to the needs of Medicine and its patients. The inevitable result is that progress in the utilization of technological advances for Medical Research and the improvement of the Practice of Medicine in the United States is significantly slowed to the detriment of the people who stand to benefit from these advances.

Many types of modern instrumentation and technology are essential to the rapid progress of medical science - including computers, X-ray equipment, CAT scanners, million electron volt electron microscopes, synchrotron radiation facilities and nuclear magnetic resonance (NMR) instruments.

I can illustrate the kind of slowdown that is occurring in this country by the developments in the field with which I am myself associated - the Biological and Medical Applications of Nuclear Magnetic Resonance. Over ten years ago Professor Paul Lauterbur of the State University of New York at Stony Brook invented a technique for NMR imaging. The potential of this technique for medical research and clinical diagnosis was rapidly recognized in the scientific community. Although Dr. Lauterbur did receive a modest amount of support to develop the necessary instruments, much more decisive support was marshalled in Great Britain and the first clinical applications of the method were reported from the Hammersmith Hospital in London, England. Today 14 instrument manufacturers are developing NMR imaging equipment for medical use, but the sources of funding of such instruments for Universities and Hospitals remain ill-defined. The hope that the costs of the instrumentation - of the order of $2 Million per unit will be defrayed by income from patient care does not take into account that for the immediate future at least the technique must be used on an experimental basis and applications must be closely tied in with further technical development. One of the most important and promising prospects in this field is the combination of imaging and the use of NMR as a non-destructive and noninvasive technique for monitoring metabolism in human subjects in health and disease. This combination of NMR techniques has an enormous potential both as a diagnostic tool and as a tool for evaluating the results of therapy in a large number of diseases. Although this potential is clearly recognized by the experts, the resources of the instrument manufacturers are concentrated on the simpler, more immediately marketable imaging equipment and sources of funds for the more sophisticated developments can not be identified. In December 1982 the National Heart, Lung and Blood Institute sent out an RFP for contracts to evaluate NMR as a method for the study of metabolism in human subjects. This RFP specifically excluded the cost of the required equipment. During the past year I chaired a faculty committee appointed by the Dean of the Stanford Medical School and charged with the responsibility of planning the future application of NMR in medical research and practice at the Stanford Medical Center. The committee, after a careful evaluation of the state of the field, recommended the establishment of an NMR Center at the Medical School. The estimated capital investment in instrumentation and facilities required for a leading developmental program in this field is in the order of $6 M - $8 M.

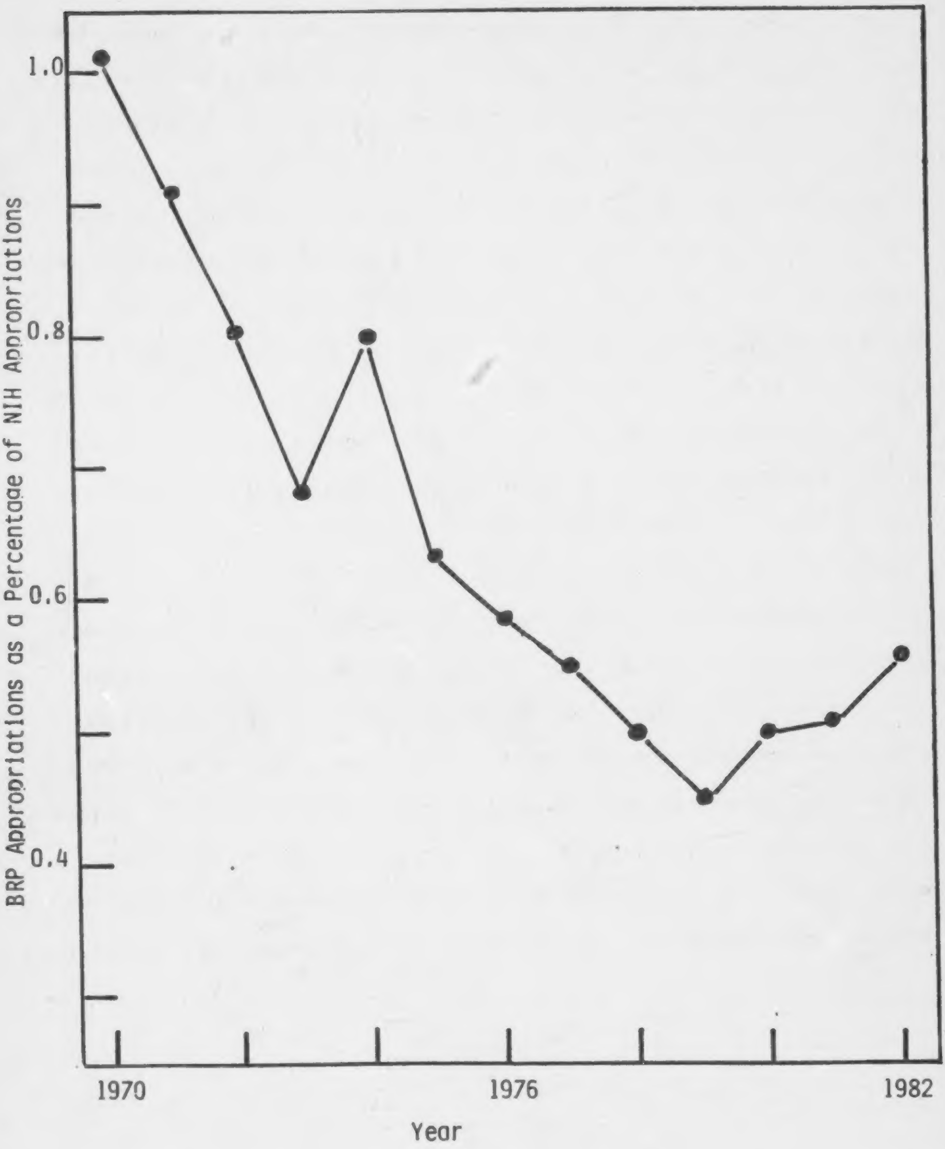
The program satisfies all the criteria for a federally funded research grant, but there are no medically oriented instrumentation programs capable of entertaining proposals requiring a capital outlay of this order of magnitude. The categorical Institutes of the NIH have on occasion funded costly advanced instrumentation for specific applications but have no instrumentation programs for the development of new instruments with a wide range of applications. The principal programs for support of instrumentation are in the Division of Research Resources - The Biotechnology Resources Program with an annual budget of $17.7 M for FY 1983 and the Instrumentation Program of the Biomedical Research Support Program with an annual instrumentation budget of $10 M for FY 1983. The budget of the BRP supports 57 instrument resources and the BMS Program has a $200,000 ceiling for instrumentation per applicant.

Recognizing the urgency of meeting the instrumentation needs of the biomedical community, Congress in 1981 mandated a report from the National Institutes of Health on shortages in Research Equipment and Instrumentation. This report, submitted in February 1982, recommended an addition of $20 M/year for five years to replenish and maintain the adequacy of the biomedical research community's needs for instrumentation. On the basis of this report a total of $12.5 M was added by Congress to the DRR budget in FY 1983. This sum though helpful is far below the estimate of need in thr report and is not adequate to meet the new needs generated by recent explosive technological developments, such as those that have occurred in the applications of NMR. Furthermore, we note with distress that no further additions as recommended by the NIH report are incorporated into the President's budget for FY 1984. Without these additions neither the needs for replacement of instrumentation nor the needs for the development of new instrumentation can be met.

We therefore strongly urge Congress to implement the recommendations of the 1982 NIH report and increase the funding of the NIH programs for instrumentation by the recommended amount of $20 M in FY 1984 and subsequent years. Without deemphasizing the need for replacement of instrumentation in the medium price range ($30,000 - $300,000), we wish to call specific attention to the rapidly rising need for more sophisticated and complex technological installations applicable to Medicine. It is clear that such installations are too costly to be provided to individual investigators on categorical research grants and must, to ensure their maximal utilization, be operated on a shared basis.

The Biotechnology Resources Program of the Division of Research Resources, operating successfully since 1962, has demonstrated the validity of the concept of shared regional or national instrumentation resources. This program concentrates on the application of the physical sciences, mathematics, and engineering to biology and medicine. Ultrasophisticated instruments, the latest state-of-the-art methods, and expert support personnel provided by the program in installations open to many users help life scientists in their efforts to decipher fundamental biological processes or combat human illness. It is the only such program in this country. These instrumentation facilities have capabilities which cut across the interests of the categorical institutes. The Biotechnology Resources Program has been singularly successful and has served as a model. However, the support it has been receiving within the NIH has not been adequate to its mission. As the attached figure shows, it has failed to keep pace with the growth of the NIH. In fact, it has shown a decline in terms of dollars corrected for inflation over the last decade.

We therefore specifically recommend (1) that the annual $5 M increment in the BRP budget requested in the 1982 NIH report be mandated for FY 1984 and subsequent years, (2) that an additional fraction of $10 M of the balance of the instrumentation funding requested in this report ($15 M) be designated for the pilot program of co-funded program project grants recommended on page 2 of the report, without institutional ceilings, as the potentially most effective means for promoting the design and development of major new technological resources that may fall beyond the scope of the existing DRR programs.


BRP Appropriations as a Percentage of NIH Appropriations
1.0
0.8
0.6
0.4
1970
1976
1982
Year

STATEMENT OF DR. RANDALL ZUSMAN, PUBLIC POLICY COMMITTEE, AMERICAN FEDERATION FOR CLINICAL RESEARCH

Senator WEICKER. Doctor, thank you very, very much for your testimony. The committee appreciates it.

The next witness is Dr. Randy Zusman, cochairman, public policy committee, American Federation for Clinical Research.

Dr. ZUSMAN. Mr. Chairman, I am Randall Zusman, assistant professor of medicine at Harvard Medical School and director of the hypertension division of the cardiac unit of the Massachusetts General Hospital.

I serve as cochairman of the American Federation for Clinical Research and associate editor of Clinical Research.

In addition to my teaching and patient care responsibilities, I am currently engaged in the study of vasoactive substances and the regulation of blood pressure.

I am here today as the representative of the AFCR, the largest clinical research organization in the United States, comprised of over 11,000 physician investigators. The AFCR's purpose is to provide a forum for the work of young physician scientists establishing themselves in the field of research.

Clinical investigators with training in both medicine and basic research provide the essential link between the research laboratory and the patient care setting. These physicians possess the insight to apply new scientific knowledge to the clinical practice of medicine, as well as to identify new problems requiring investigation.

The mission of the AFCR is particularly important today when the number of physicians pursuing research careers is steadily declining. The NIH is the key Government agency funding clinical research.

It is a pleasure to quote your own words before the American Diabetes Association recently, in which you stated:

> If there is an agency that gets the most bang for its buck, it is the NIH. Its mission is the most difficult of any in Government—to combat and prevent the major killing and disabling diseases of our time.

Among the achievements of the NIH-supported research are the production of successful vaccines against polio, pneumococcal pneumonia, rubella, and hepatitis; combined chemotherapy for the treatment of cancer; improved medical and surgical treatment of cardiovascular disease, and dialysis for patients with kidney failure.

It is worth noting that the NIH has supported the work of 70 Nobel Prize-winning scientists.

The AFCR believes that adequate and stable financial support is essential to maintain the Nation's biomedical research enterprise. The foundation of a strong research enterprise depends on the continuing infusion of young, creative investigators into the research manpower pool. Our objective is to assure a steady level of support to maintain continuity in the conduct of scientific research and to encourage young physicians to enter the field.

The President's fiscal year 1984 budget request of an increase of $73 million for the NIH can only result in a significant slowdown in the flow of new basic medical knowledge, which serves as a basis for prevention and treatment of disease.

On the other hand, the American Federation for Clinical Research is most appreciative of the commitment which Congress has demonstrated in the past to the biomedical research effort, particularly in these difficult economic times.

I would like to take this opportunity to focus more specifically on two aspects of the NIH budget: grants for extramural investigator-initiated research and for research training.

Extramural investigator-initiated grants are the mechanism through which NIH funds highly innovative basic research. In the past few years, efforts have been made to assure full funding for a minimum of 5,000 new and competing renewal grants.

The AFCR maintains that support for these grants should be the highest priority of the NIH but has become increasingly concerned about two points.

The 5,000 figure has come to be construed as a ceiling rather than as it was intended—a minimum number of awards necessary to assure creative science and opportunities for new investigators.

Although this number of grants has been attained, it has not been accomplished with an adequate level of support per grant. In recent years, support for this number of grants has been provided only through across-the-board percentage cuts for noncompeting grants, reductions from study section-recommended costs for new and competing grants, and shifts from other NIH programs such as research centers, biomedical research support grants, and clinical research centers.

We urge Congress to give special attention to maintaining a strong individual investigator-initiated research program. Support for these new and competing grants should be at a level sufficient to fully fund a stable number of grants, provide for modest growth, and continue to support other NIH programs as appropriate.

The National Research Service awards program is designed to support research training in order to meet future research manpower needs. Since 1979, when 10,928 research trainees were supported, the number has steadily declined.

The administration recommends funding sufficient to support only 9,100 trainees. There are considerably fewer trainees available than recommended by the National Academy of Sciences.

Given this, with the President's proposal, we would fall far short of the number of researchers we should be training to meet future manpower needs. This downward trend in funding for research training will drive promising physicians away from research to other fields of endeavor.

In fact, this trend has already begun. A diminishing proportion of physicians is applying for clinical research support and fewer are interested in being trained as researchers. The perception of instability in the research field and less than adequate stipends are among the causes of this trend.

The AFCR recommends that NIH funding be sufficient to support at least 10,000 research trainees in fiscal year 1984.

Health research has contributed substantially to the well-being of our Nation's citizens and economy. Each dollar invested in medical research is estimated to produce a $13 savings from benefits such as reduced incidence of illness, reduced medical costs, and increased life expectancy.

Such research has also contributed to the development of minicomputers, techniques for food preservation, and telecommunications.

The administration's budget proposal would seriously jeopardize the national research effort, both in terms of lost research ideas and future research manpower. The AFCR urges the appropriation of NIH funding at a level to avert a potentially damaging and destabilizing effect on the medical research effort and to continue to make scientific achievements which improve the health and well-being of our Nation.

I thank you for the opportunity to share the AFCR's concerns with you and would be happy to answer your questions.

PREPARED STATEMENT

Senator WEICKER. Dr. Zusman, thank you very much, and I think your statement is complete. If there were more time, I would have a lot of questions to ask because I think much of the manipulation—which I guess is the proper word—of the budget in the matter of grants and what was cut and what was added really relates very directly to your testimony. We will read it in detail.

Dr. ZUSMAN. Thank you, sir.

[The statement follows:]

STATEMENT OF DR. RANDALL ZUSMAN

My name is Randall Zusman. I am assistant professor of medicine at Harvard Medical School and director of the hypertension division of the cardiac unit at Massachusetts General Hospital. I serve as cochairman of the American Federation for Clinical Research (AFCR) public policy committee and associate editor of Clinical Research. In addition to my teaching and patient care responsibilities, I am currently engaged in the study of vasoactive substances and the regulation of blood pressure.

I am here today as the representative of the AFCR, the largest clinical research organization in the United States comprised of over 11,000 physician investigators. The AFCR's purpose is to provide a forum for the work of young physician scientists establishing themselves in the field of research. Clinical investigators with training in both medicine and basic research provide the essential link between the research laboratory and the patient care setting. These physicians possess the insight to apply new scientific knowledge to the clinical practice of medicine as well as to identify new problems requiring investigation. The mission of the AFCR is particularly important today when the number of physicians pursuing research careers is steadily declining.

The NIH is the key Government agency funding clinical research. As Senator Weicker pointed out in a recent address to the American Diabetes Association, "* * * If there is an agency that gets the most bang for its buck, it is the NIH. Its mission is the most difficult of any in Government—to combat and prevent the major killing and disabling diseases of our time * * *" Among the achievements of the NIH-supported research are the production of successful vaccines against polio, pneumococcal pneumonia, rubella, and hepatitis; combined chemotherapy for the treatment of cancer; improved medical and surgical treatment of cardiovascular disease, and dialysis for patients with kidney failure. It is worth noting that the NIH has supported the work of 70 Nobel Prize-winning scientists.

The AFCR believes that adequate and stable financial support is essential to maintain the Nation's biomedical research enterprise. The foundation of a strong research enterprise depends on the continuing infusion of young, creative investigators into the research manpower pool. Our objective is to assure a steady level of support to maintain continuity in the conduct of scientific research and to encourage young physicians to enter the field. The President's fiscal year 1984 budget request of an increase of $73 million (1.8 percent) for the NIH can only result in a significant slowdown in the flow of new basic medical knowledge which serves as a basis for prevention and treatment of disease. On the other hand, the AFCR is most appreciative of the commitment which Congress has demonstrated in the past to the biomedical research effort, particularly in these difficult economic times. I would like to take this opportunity to focus more specifically on two aspects of the NIH budget: Grants for extramural investigator-initiated research and for research training.

Extramural investigator-initiated grants (R–01's and P–01's) are the mechanism through which NIH funds highly innovative basic research. In the past few years, efforts have been made to assure full funding for a minimum of 5,000 new and competing renewal grants. The AFCR maintains that support for these grants should be the highest priority of the NIH but has become increasingly concerned about two points:

(1) The 5,000 figure has come to be construed as a ceiling rather than as it was intended—a minimal number of awards necessary to assure creative science and opportunities for new investigators.

(2) Although this number of grants has been attained, it has not been accomplished with an adequate level of support per grant. In recent years, support for this number of grants has been provided only through: across-the-board percentage cuts in approved award rates for noncompeting grants; reductions from study section-recommended costs for new and competing grants; and shifts from other NIH programs such as research center, and biomedical research support grants. We urge Congress to give special attention to maintaining a strong individual investigator-initiated research program. Support for these new and competing grants should be at a level sufficient to fully fund a stable number of grants, provide for modest growth, and continue to support other NIH programs as appropriate.

The National Research Service awards program is designed to support research training in order to meet future research manpower needs. Since 1979, when 10,928 research trainees were supported, the number has steadily declined. The administration recommends funding sufficient to support only 9,100 trainees. The National Academy of Sciences recommended that 10,975 biomedical researchers be trained in fiscal year 1983. Given this, with the President's proposal, we would fall far short of the number of researchers we should be training to meet future manpower needs. This downward trend in funding for research training will drive promising young physicians away from research to other fields of endeavor. In fact, this trend has already begun; a diminishing proportion of physicians is applying for clinical research support and fewer are interested in being trained as researchers. The perception of instability in the research field and less than adequate stipends are among the causes of this trend. The AFCR recommends that NIH funding be sufficient to support at least 10,000 research trainees in fiscal year 1984 (that is, $17 million over the President's request).

Health research has contributed substantially to the well-being of our Nation's citizens and economy. Each dollar invested in medical research is estimated to have produced a $13 savings from benefits such as reduced incidence of illness, reduced medical costs, and increased life expectancy. Such research has also contributed to the development of minicomputers, techniques for food preservation, and telecommunications. The administration's budget proposal would seriously jeopardize the national research effort both in terms of lost research ideas and future research manpower. The AFCR urges the appropriation of NIH funding at a level to avert a potentially damaging and destabilizing effect on the medical research effort and to continue to make possible scientific achievements which improve the health and well-being of our Nation. I thank you for the opportunity to share the AFCR's concerns with you and would be happy to answer questions.

STATEMENT OF DR. RONALD HUNT, DVM, PROFESSOR OF COMPARATIVE PATHOLOGY, HARVARD MEDICAL SCHOOL, AND DIRECTOR, NEW ENGLAND REGIONAL PRIMATE RESEARCH CENTER

ACCOMPANIED BY DR. D. MARK HEGSTED, ASSOCIATE DIRECTOR FOR RESEARCH

Senator WEICKER. Thank you very much. The next witness before the committee is Dr. Ronald Hunt, DVM, professor of comparative pathology, New England Regional Primate Research Center, accompanied by Dr. D. Mark Hegsted, the associate director for research.

At this time the Chair will be assumed by the Senator from Wisconsin, Senator Proxmire.

Senator PROXMIRE [presiding]. Thank you, Lowell.

[Pause.]

Senator PROXMIRE. We are going to set up some new lights, Doctor.

Incidentally, while you are waiting, we have a Primate Research Center at Madison that you may be familiar with.

Dr. HUNT. Yes, sir.

Senator PROXMIRE. And we are very proud of it.

Dr. HUNT. Yes; I have visited it.

Senator PROXMIRE. You have?

Dr. HUNT. Yes; I have.

Senator PROXMIRE. When were you there?

Dr. HUNT. I was last there—I believe it was a year ago, in the spring.

Senator PROXMIRE. What month was it—just about April or May? The reason I ask is because if you come late in the spring Madison is marvelous; if you come early, it is pretty rugged.

Dr. HUNT. It was on the later side rather than the earlier side.

Senator PROXMIRE. That is good.

Dr. HUNT. That is not totally different than New England.

Senator PROXMIRE. I am very proud of Madison. It is a beautiful town.

Dr. HUNT. Handsome university as well.

Senator PROXMIRE. Yes; it is a great university.

Incidentally, what institution are you with?

Dr. HUNT. The institute? We are with the Division of Research Resources of NIH.

Senator PROXMIRE. I see, very good.

All right, sir. All set? Go right ahead.

You understand the rule is 4 minutes?

Dr. HUNT. Yes, sir.

As Senator Weicker indicated, I am a professor at the Harvard Medical School and director of the New England Regional Primate Research Center, and I am here representing all seven of the primate research centers.

I wish to bring some of the aspects of their programs to this committee's attention, in that the centers represent one of the most unique animal resources within this country.

They not only address important issues in health care and disease prevention, but they also address many important problems with respect to conservation of primate species. The research programs touch on health programs of concern to each of the categorical institutes of the National Institutes of Health—the programs in heart disease, in cancer, ulcerative colitis, blindness, mental retardation, drug addiction—a great diversity of diseases and conditions, and most recently the acquired immune deficiency disease, or AIDS.

Each center is small, but is able to engage in a rather diverse research program because they are really not islands unto themselves. They are each, as you know, affiliated with a major university, my own being the Harvard Medical School, but beyond that they also provide a regional resource available to investigators across the country at large, who can bring programs which have been reviewed and funded most generally by a categorical institute of the National Institutes of Health, but conduct the animal aspects of their programs within these regional resources. In my own center we have programs from Mount Sinai Medical Center, Boston University, Sloan-Kettering, the Dana-Farber Cancer Institute, the Department of Agriculture, Food and Drug Administration, Yale, University of Connecticut, and several more.

At any one time, there are some 130 odd scientists from other institutions conducting their research within the center. This provides, I believe, a very unique concept in the provision of the necessary resources for the conduct of approved and funded research.

In addition, the centers have a very unique role, in that they are one of the few organizations in the country that are approved under NIH to directly study animal diseases themselves.

This becomes exceedingly important with respect to the preservation of many rare and endangered species of nonhuman primates. Without research and the knowledge on how to breed these animals, they are going to be lost. Some will go extinct, and that in itself I think is something we should have concern with.

It is a double-edged sword because many of these species do have attributes which could assist in solving many important health problems of human beings; and I will give as an example a species known as the cotton top marmoset, a small monkey from South America, which is the only animal known in the entire animal kingdom that is susceptible to the Epstein-Barr virus, a virus which is known to cause infectious mononucleosis and it is thought to cause cancer in human beings.

Marmosets cannot be used in these studies because they are endangered. We have to learn how to breed them until we have a large number of this colony, such that they can be used.

The same species also develops a naturally occurring chronic ulcerative colitis that goes on to cancer of the colon. This is an exceedingly important disease of human beings, and we have had very little progress in understanding or treating the disease because there is no animal model.

So we have to have programs that can fund an understanding of these species so we can preserve them for the future. Otherwise, they will be lost.

None of the categorical institutes are going to fund this type of program, how to breed and preserve species. So it becomes dependent upon the Division of Research Resources.

The centers are considerably underfunded; at the moment approximately $7 million underfunded. Through the NIH peer review system, we have a recommended budget of something over $26 million. The current congressional appropriation is something a little over $19 million.

I would like to stress that those dollar figures include all costs, including all the indirect costs, in contrast to most direct awards for research. That includes heat and oil and all their ancillary activities.

I know the time is very short, but I would like to bring the committee's attention—and I am sure you are well aware—that there has been a number of protests, as well as deliberations by Congress, to improve animal care and to spend millions of dollars to create alternatives to animal care, and all the while existing programs remain seriously underfunded.

The primate research centers have a very high quality program in animal care, among the best in the United States, but they are in jeopardy without adequate funding, and I think if Congress is taking any of these issues seriously, then their first priority should be to see that existing programs for animal care and the necessary research to improve animal care are adequately funded.

So I would urge the committee to fund the primate centers program at the recommended and improved NIH level.

Thank you.

Senator PROXMIRE. Thank you very much, Dr. Hunt.

I especially appreciate your reference to the marmoset. That was a fascinating point you made, that these are a rare species that can be used for a purpose that is so critical for all of us.

I think you are very wise to also mention the concern that a lot of people have about animal care and humane treatment of animals. That is a great concern of many of us, and it is good to know that you are sensitive to that and doing your best to provide sanitary care with as little pain for the animals involved as possible.

Thank you very much for an excellent presentation.

Dr. HUNT. Thank you, sir.

[The statement follows:]

STATEMENT OF DR. RONALD HUNT

I am Dr. Ronald D. Hunt, Director of the New England Regional Primate Research Center and Professor of Comparative Pathology at the Harvard Medical School, and with me is Dr. D. Mark Hegsted, Associate Director for Research at the Center and Professor of Nutrition, Emeritus, Harvard School of Public Health and Lecturer on Pathology at the Medical School. It is a privilege to appear before you as representative of the seven Regional Primate Research Centers.

In 1960 Congress created the seven Regional Primate Centers, recognizing the unique and indispensible role that primates provide in understanding human disease. As you are no doubt aware, there are many serious health problems which cannot be effectively studied with human patients. The primates are the closest relative to man and have many characteristics and disease processes similar to man's and quite distinct from those of other common laboratory species. If many problems are to be effectively studied, an appropriate animal model must be available. In the various species of monkeys, characteristics of resistance or susceptibility to various diseases vary substantially, so that the 200 species of primates provide a broad scope of unique opportunities for comparative research not otherwise available. Only a few examples will include cancer of colon in marmosets; susceptibility to viral infections including potentially cancer-causing viruses of man; susceptibility to atherosclerosis and hypertension, the major killer of American; diabetes in macaques; vision defects; asthma, emphysema and respiratory diseases of the lung; and most recently recognized, acquired immunodeficiency syndrome or AIDS.

Not only are the primates an indispensable tool for the study of human disease, many of the species are now endangered or relatively unavailable to investigators. There appears to be no alternative to the unique resources that the Primate Centers provide in the preservation of some of these species and provision of appropriate animal models for various investigators. Unfortunately, our capabilities for breeding some of these species are limited and relatively unsuccessful: our understanding of the nutritional requirements, appropriate environments, breeding habits, etc., will have to be improved if these resources are not to be lost.

The Primate Centers provide this unique resource to many investigators. For example at the New England Center, in addition to a core scientific staff of 24 Harvard Medical School faculty, the Center has collaborative programs at the present moment with 139 investigators representing 36 institutions. These include Tufts University, University of Connecticut, Yale, Massachusetts General Hospital, Mt. Sinai Medical Center in New York, Brown University, Bowman-Gray School of Medicine, Case Western Reserve, Tulane, Stanford, University of Maryland and two foreign laboratories. Most of these programs are supported by National Institutes of Health grants to the investigators. In their own institutions, these investigators have limited or no capacity to obtain or house primates. Thus many research efforts of high priority to the N.I.H. will be jeopardized if the Primate Centers cannot provide the expected support.

This year there has been an extensive peer review of the facilities provided by the Primate Centers and of their research programs. This review has demonstrated deteriorating physical plants and facilities and an insufficient staff to meet the recommended programs. The over-all review has resulted in Council-recommended budget of $26,342,128 as compared to the current year's funded budget of $19,272,000 for operation of the Director's office and all seven centers. It should be stressed in evaluating these figures that unlike research grants they include not only the core staff research programs but all overhead costs as well. The indirect costs, such as heat, light, maintenance, security, administration, etc. are a part of the appropriation and not subject to negotiation.

Mr. Chairman, the Primate Centers require renovation of facilities to meet Federal standard of animal care even now being expanded by other legislation before Congress; they need replacement of sewers and repair of boilers and air conditioning equipment which were included only in the original appropriations back in the early '60's — now at least 20 years old; they need modifications to improve energy efficiency, and replacement of much research equipment which is already obsolete or worn out.

In conclusion, we believe that the relatively modest request recommended by Council of $26,342,128 to support this resource -- which, in relative terms, is far below the budget of 1969 -- deserves the special attention of this Committee. The relatively small budget for all seven Centers supports many more millions of dollars of additional government-sponsored biomedical research. We hope to have made the Committee aware that the issues cited are now critical and many years of effort and much future research will be lost if appropriate support is not made available.

It is a very small investment compared with the rewards of improved health which Primate Center research has given our Nation.

Thank you.

STATEMENT OF DR. MICHAEL W. FOX, SCIENTIFIC DIRECTOR, HUMANE SOCIETY OF THE UNITED STATES

Senator Proxmire. Our next witness is Martha Hamby, director of legislative activities, Humane Society.

[Pause.]

Senator Proxmire. You obviously aren't Martha Hamby.

Dr. Fox. No, sir. I am speaking in her place.

My name is Dr. Michael Fox. I am the scientific director of the Humane Society.

Our scientists were away on a conference and we were not expected back, but here we are.

I represent the Humane Society of the United States, which has 200,000 members. We are concerned——

Senator Proxmire. That's an appropriate juxtaposition of witnesses, isn't it?

Senator Proxmire. Yes, indeed. Very good.

Dr. Fox. We're concerned about a number of issues, sir. The use of laboratory animals to study the biological mechanisms of the major degenerative diseases that afflict us is the basis of profitable interventive rather than preventive medicine. The primary beneficiary of such public-funded research is not the public but the biomedical industry, and at the expense of human health and animal suffering, when the primary focus of research and practice is preventatively oriented.

Animal and human research studies have shown the connection between a number of degenerative disesases, such as diabetes, arthritis, birth defects, and stroke, with such factors as improper diet, environmental pollution, and environmental stress.

The solutions to these human health problems are not biological ones that can be found in the animal research laboratory. They are primarily social, psychological, economic, and political.

The primate centers are not contributing significantly in this regard.

We can agree that animal research has certainly helped people with various disorders. But from the perspective of holistic medicine, the contributions have been relatively insignificant.

Primates in laboratory cages confined in a space 2 by 3 feet engage in self-mutilation, they become hyper-aggressive, they have caged stereotypes, they masturbate constantly. They are not in a normal state for valid biomedical research to be done on them.

I would ask you and the gentlemen and ladies here, why are these standards accepted? The interpretation of many philosophers and scientists and doctors is that this is a reflection or a Cartesian mechanistic mind set in the biomedical establishment that ignores the important emotional, social, and environmental variables in the laboratory animal model. It is these variables that need to be addressed if we are going to improve human health.

The position of the Humane Society is that we are not opposed to animal research per se. We advocate alternatives. We also seek appropriate funding to develop such alternatives to the use of primates and other animals species.

We also have evidence that both the Delta and Oregon Primate Centers should be closed and the funds siphoned into improving the environmental, social, and emotional care of primates in the research centers, which will improve the quality and validity of research being done.

We are opposed to and question research on animals that is of no real benefit to alleviating the major diseases that afflict humanity. We are opposed to all animal research, with or without pain, fear, or suffering, which leads to interventive, symptom-oriented medical application in humans at the expense of research on disease prevention, especially behavioral and econological medicine.

Research prioritization is basically flawed, because for political and economic reasons, the major causes of human disease, from industrial pollutants and agrichemicals, improper diet, to contaminated food, air, and water and emotional distress in people, are not being addressed. The answers are not in the animal laboratory, nor are they in primate research.

Preventive medicine, like cleaning up the environment, is not profitable. The use of laboratory animals in research may be acceptable if the animals are kept under conditions which cause no pain, fear, or suffering.

These humane principles are also the principles of good research.

In some of the primate centers, the animals are incarcerated in small cages or else they're strapped in chairs, sometimes for months on end.

The state of the animal's mind affects the state of its body and, therefore, induces all kinds of experimental variables. These are generally swept under the table.

Second, the research must be done humanely and must be relevant. Because of the narrow mechanistic mind set in the biomedical research industry, social, emotional, and environmental variables and nutritional variables are usually dismissed.

If you would like to eat a diet of laboratory primate chow every day that has been heat processed and so on, I think it would certainly affect your behavior and your body.

Scientific validity and relevance is subjectively determined and instrumentally rationalized through consensus. It's a subject state that everything is OK with these standards.

Our plea is that if we're going to use primates in research they must be properly cared for and the research being done on them must be valid.

This mechanistic view is the major flaw of the grant peer review system and husbandry standards that are acceptable to the establishment in these primate centers.

As the welfare of laboratory primates is a call to conscience, so the animal welfare movement is a call to the biomedical industry for public accountability.

Senator PROXMIRE. Thank you very much, sir. I appreciate this. And as I say, I think your testimony was perfectly timed.

You and Dr. Hunt agree on many things. You agree that the animals should be treated humanely and avoid pain as much as possible and that animal research is—you concede animal research is necessary.

Mr. Fox. But with the present mind set of the biomedical establishment, the relevance of this research is highly questionable. And I believe that this should be investigated, not simply by scientists, but by ecologists, philosophers, and others.

Senator Proxmire. Dr. Hunt's position, as I understand it, was that they agree with much of what you say, but they feel they have to have more funding in order to achieve——

Mr. Fox. Well, I think they've been doing a lot of——

Senator Proxmire. And you gave another alternative, which is to close down the——

Mr. Fox. The two primate centers.

Senator Proxmire [continuing]. Two of the primate centers and to use that money.

Very good. Thank you very much.

Mr. Fox. Thank you.

Senator Proxmire. Your statement will be included in the record at this point, along with other statements submitted for the record on appropriations for the NIH Division of Research Resources.

[The statements follow:]

STATEMENT OF JOHN MCARDLE, DIRECTOR, LABORATORY ANIMAL WELFARE, THE HUMANE SOCIETY OF THE UNITED STATES

MR. CHAIRMAN, I am John McArdle, Director of Laboratory Animal Welfare for The Humane Society of the United States and a scientist with over eight years of experience using non-human primates in biomedical research. I am pleased to have the opportunity to speak to you on behalf of the 80 million laboratory animals used annually in the U.S., and a large number of taxpayers who are becoming increasingly oncerned about this issue. Although we are not opposed to legitimate research, we strongly disagree with the N.I.H. and the biomedical research community on what constitutes adequate justification, standards of performance, and protection of animals used in research.

Laboratory animals are utilized in basic research, product testing, and education. Although alternatives are presently available for most uses in the latter two categories, bureaucratic inertia and the maintenance of outdated traditions have delayed their implementation. The record of the N.I.H. in promoting and developing alternative methodologies suitable for basic research is inadequate. We have two proposals that will effectively improve the quality and reliability of tax supported biomedical research, while significantly reducing the numbers and cost of animals used.

PROPOSAL 1: Closing of Primate Research Centers

We ask that the Division of Research Resources phase out the Oregon and Delta Regional Primate Research Centers for reasons of relative inaccessibility, high disease and mortality rates, and geographical redundancy. We further ask that researchers at the remaining PRCs be required to recover their research costs by the same mechanisms employed by the remainder of the scientific community. Funds saved by these actions should be specifically reallocated to promote the development of new alternative technologies for biomedical research.

Discussion

Although primates represent a small fraction of the animals utilized in biomedical research, The Animal Resources Program of the Division of Research Resources spends the majority of its budget (75% in 1981) on core support for the handful of scientists at the PRCs. These researchers have an unfair competitive advantage over their colleagues in academia, since both salary and maintenance of physical facilities are guaranteed. Without the usual controls provided by merit-based competition, inferior personnel and research can be sheltered from the usual mechanisms for dealing with poor quality science.

The PRCs were established "to ensure that the special environments required for biomedical studies with primates are available to U.S. scientists." They were designed to serve as national resources for the U.S. biomedical research community, but they have consistently failed to achieve that goal. A British government study in 1969 noted that the PRCs' visiting scientist programs were "surprisingly small" and "do not provide a service outside their own organization." They summarized the PRC program by noting "the amount and quality of work emerging from the N.I.H. sponsored programmes does not appear to justify the great expense incurred" and that a similar PRC program in England "would not be in the best interests of the majority as it would tend to attract available funds to the minority." In contrast, they noted that the LEMSIP (Laboratory for Experimental Medicine and Surgery in Primates) primate facility had an excellent performance record, at substantially lower cost than the PRCs.

A 1976 Division of Research Resources commissioned review of the PRC observed that the problems with the extent of utilization by the outside scientific community and poor quality of research within the PRCs still remained as general characteristics of the program (with only one exception).

Numbers of Visiting and Collaborative
Scientists and Trainees
FY74

	Visiting	Collaborating	Trainees
Maximum	5	173	80
Minimum	0	15	0
Mean	2	62	23

Some of the PRCs they examined were "heavily committed to more applied, less original research" which reduced the overall quality of research resulting from the DRR core support, and that "efforts aimed at monitoring the excellence of research have not been entirely successful." As we have proposed above, they suggested that the research conducted at the PRCs "be re-examined with a view towards achieving excellence throughout the program, even if this leads to the phase-out of one or more centers."

An additional DRR review in 1979 noted that: 1) some of the PRCs were still not accredited, due to "inadequate housing facilities," 2) use by outside scientists had declined even further, and 3) "the centers have not become the unique centers of academic excellence envisioned for them at the time of their creation." Examination of the 1981 annual reports from the PRCs indicates that these problems persist today.

For over twenty years the PRCs have failed to perform as originally intended. Several hundred million dollars have been wasted supporting such cruel and scientifically unjustifiable projects as toxicity testing of previously banned substances, drug and alcohol abuse, and experimental psychological research. These were basically a waste of time, money, and intellectual energy. PRCs are still removing increasingly endangered primates from their natural habitats, despite over two decades of "research" into proper breeding and care of primates in captivity. One need only to visit the world's leading zoological parks to learn how to breed and maintain primates.

As noted by the British fourteen years ago, the PRCs have not justified their high cost, in dollars and primates. We believe that money would be more effectively spent developing alternative techniques with direct applicability to human problems.

PROPOSAL 2: Development of New Alternative Technologies

We ask that the Division of Research Resources reallocate $10 million for the development and promotion of new alternative technologies, specifically designed to replace animals currently being used in biomedical research.

Discussion

The principal objective of the DRR is the creation and development of new resources for the biomedical research community. We want the DRR to pursue that goal by changing its previous perspective and actively encouraging the replacement of traditional methods of biomedical research with alternative technologies that focus on the target animal (i.e. tissue-culture, human cells), rather than promoting the often questionable practice of inter-species extrapolations, which typify the "animal models" appraoch to understanding biological problems.

Although there will always be some areas of research that require intact laboratory animals, insufficient emphasis has been placed in biomedical education and Federal funding on either the utilization of existing or the development of entirely new alternative methods. The principal factor restricting the wider adoption of alternatives is the attitude of the biomedical research community. Intellectual tradition, rather than necessity, and a lack of commitment by the appropriate Federal granting agencies to developing new methods encourages the continued excessive use of laboratory animals.

Although some alternative techniques currently in use were developed as "by products" of other research projects, this has not always and need not continue to be the accepted approach. If funds were specifically allocated to develop alternatives, individual scientists would apply for and subsequently produce the new methods needed to improve the quality and reliability of biomedical research.

The work of professor Joseph Leighton, Medical College of Pennsylvania, clearly illustrates how this process would work. In the past few years millions of rabbits have been used in the Driaze test by having corrosive and irritating substances placed in their eyes. Results of this test are ambiguous and provide little protection for the American consumer, while causing extreme suffering in the rabbits. Since 1911, it has been known that the choriallantoic membrane of chicken eggs has an inflammatory response to irritants, an intact circulatory system and is lined by cells similar to those on the cornea of the eye. Professor Leighton was the first to realize that the chicken egg was a potential alternative to the rabbit. Once provided with sufficient funds, he was able to develop this approach and is now clearly demonstrating responses to irritants equal to or superior to those previously observed in rabbit eyes. As is typical of alternative techniques, the egg tests are highly reliable, faster and significantly less expensive. The use of laboratory animals requires caretakers, animal facilities, cages, food, bedding, veterinary care and often considerable cost to purchase the animals from commercial breeders or dealers. Any time an alternative replaces a significant number of animals, there will be substantial savings of research funds, which are already in short supply.

The use of whole-animal models in biomedical research was orginally proposed to study infectious diseases. Although this was an appropriate application of the "model" concept, alternative techniques (cell and tissue culture) are now available to conduct such research. However, the "animal model" approach is now inappropriately applied to an ever expanding series of research topics. Cancer studies are an excellent example of this problem. Cancer is basically a species-specific malfunction at the cellular level, and is best studied by examining those specific cells. If one is concerned about human cancer, one should work with human cancer cells, not with malignancies in rats, mice, or some other non-human laboratory animal. Dr. Irwin Brass of the Roswell Park Memorial Institute, in reviewing the entire field of cancer research, concluded that "there is no good factual evidence to show that the use of animals in cancer research has led to the prevention or cure of a single human cancer."

Although alternative techniques presently exist to maintain and study most of the appropriate cancer cell types, development of new methods, approaches and philosophies in biomedical research, and deemphasizing the traditional bias towards laboratory animals, may succeed where the previous animal model approaches have failed.

The Yerkes Regional Primate Research Center
Emery University
Atlanta, Georgia

Comments on the Center's research report to the
National Institute of Health dated May 13, 1982,
for the period of January 1, 1981, to December 31, 1981.

by

Dr. M. W. Fox
Scientific Director
The Humane Society of the United States
Washington, D. C.

The Yerkes Regional Primate Research Center has a colony of 1,300 monkeys and 190 great apes. The research highlights reported by the director, Dr. Frederick A. King, included a study by H. M. McClure on birth defects in rhesus monkeys that involved the prenatal injection of a drug called cytoxan, which causes oral and facial malformation in the developing monkey. This project was supposedly a useful model to help in the surgical correction of humans with similar problems.

A second highlighted project was a proposed model of human cystic fibrosis. This project was set up on the basis of one animal dying from a disease resembling the disease in man, this single case having a possible, but not a proven heritable basis. A rhesus colony is now being developed with the hopes that this disease will appear at a greater frequency. As yet, no such "model" monkeys have been born.

A third highlighted study was on the fertility of orangutans and gorillas, because these animals have low fertility in captivity. It is stated, "In the interest of conservation, it is extremely important that these species be bred in captivity." It is difficult to see how improved breeding in captivity is going to help the conservation of these species in the wild. Pigmy chimpanzees (Bonobos) are now being studied by J. F. Dahl because of their similarities to human beings, again with the idea of providing the biomedical industry with yet another human "model" for further research development.

Although this Center was established in 1961, we find twenty years later, continuing research on trying to improve the fertility and productivity of primates in the Center for supply to biomedical researchers. Many government funded projects are developed to gain the understanding of mechanisms and control for reproductive behavior and endocrine function, and an in vitro fertilization and implantation project is under way in order to develop a model to help humans with fertility problems and for teratogenic research. It is surely a zero health priority to enhance human fertility, considering the problem of human overpopulation in the world, but it is a profitable one for those who can afford artificial fertilization treatment. D. E. Martin has gone so far as to electrostimulate chimpanzees, "To improve the sexual rehabilitation of human paraplegics." Developing an animal model to help treat physiological impotency in spinal injured humans again is of questionable medical significance in terms of alleviating human health problems. This project dovetails with research to develop techniques to artificially breed chimpanzees because of the difficulties of breeding them under the impoverished conditions in captivity.

A chimpanzee and rhesus research project is ongoing to develop animals for the NASA Space Lab project. The use of primates for space exploration would hardly seem relevant to human health, since space exploration is primarily for economic and military purposes. Three chimpanzees in this project were implanted with multi-channel hard wire biotelemetry recording systems. The concluding factor showed that a different implant system is needed, rather than this system that had entailed "hard wires" coming out of these animals' rib cages, since infections resulted and all three apes died of sepsis. These three chimpanzees were used for trial flight and space stress studies.

J. G. Herndon has a variety of projects, including brain recording studies and shock studies in primates, and studies of endocrine variables in primate social behavior, which entail prolonged restraint of animals in chairs. This investigator addresses the problem of the effects of having to capture the animals in order to take blood samples, and finds that repeated capturing is necessary to get "stable levels." One may wonder what validity such readings have of animals terrified of being captured and restrained for sampling purposes.

E. O. Smith is studying very broadly the effects of various psychoactive drugs on social behavior in primates. As with Herndon's project, one may wonder about the relevance of this study. It would seem that these studies, along with M. S. Blank's on pituitary and adrenal hormones in social groups and the variables of capture and restraint on blood levels, and L. D. Byrd's project on "drug abuse," (evaluating the effects of psychoactive drugs on the central nervous system and behavior in chimpanzees and squirrel monkeys) are designed to develop baseline parameters and recording techniques for future possible application and systems modeling, since no direct benefits to human health are evident. There seems to be no end to this kind of promissory "basic research."

A. D. Smith's project on aging and recall in old chimps in the colony has questionable relevance, considering the highly deprived and traumatic past of these animals. Another example of such dubious modeling of human health problems is in their aged Macaca nigra colony in which, with increasing age, diabetes occurs. This problem of unknown and uncontrolled etiology, justifies the perpetuation of such animals for further parametric tinkering. Another old population of rhesus monkeys that has been subjected to radiation is still being maintained, and as the director quotes, "This unique rhesus population continues to be a good source of non-human primate tumor-tissue as twenty-two of forty-seven (40%) animals (sic) have died, have had neoplasms."

The real medical value of all this research is extremely difficult to demonstrate. Perhaps there are a few exceptions, such as the development of a melanoma vaccine in chimpanzees, and a study on reshaping the cornea in rhesus monkeys called refractive keratoplasty. Considering the fact that melanoma can be rapidly diagnosed, and considering the fact that people can wear prescription glasses or relatively effective contact lens, both of these projects are of dubious value. In relation to the range of chronic degenerative diseases afflicting the human population, these projects are of little relevance and only provide profitable interventive and symptom oriented treatments for a very small segment of the populace (see Table I).

As a breeding center for primates for some twenty years, the Yerkes Primate Center does not seem to be doing its job. Of 133 chimps in the colony, four died in this period, and there were only 10 births. Of 18 gorillas, there were two births and one death. And of 32 orangutans, there were 3 deaths and 3 births.

On page 166 of the report it is clearly indicated that 62 primates died. But on page 173, 149 primates were autopsied by the veterinary division (2 not from the Center). (They report this to be an improvement of 27% from mortalities and necropsies done in 1980.) However, on summary tables pages 169 - 171, only 138 necropsies are listed. These inconsistencies seem to suggest that primate mortalities are high and many go unrecorded. Of those that were recorded, the greatest number of deaths were associated with clinical problems -- 37.6% of the total postmortems done. Abortions, stillbirths, and neonatal deaths represented 38.3% of the total mortalities. Significantly, a high 17.4% were associated with death from experimental procedures, and a remaining 5.4% were deaths due to accidents, fights, or exposure, and the remaining 1.3% represented necropsies done on two other animals that were not from the Center.

In conclusion, this Center is clearly not contributing in any significant way to improving human health. The experiments are of little medical relevance, causing unnecessary pain, sickness, suffering, deprivation, and deaths: deaths at a rate that the Center cannot even quantify with accuracy. And so one must question the accuracy and validity of experimental data derived from these animals at their emotional and physical expense, and at great expense to the tax-paying public. The primary beneficiaries of this Center are its research community and the biomedical industry that this Center serves.

TABLE I

1981

Rank	Cause of Death in U.S.	Death Rate	Percent of Total Deaths
1	Diseases of the heart	330.6	38.2
2	Cancer	184.3	21.3
3	Stroke	71.7	8.3
4	Accidents and adverse effects	44.5	5.1
	Motor vehicle accidents	22.8	2.6
	All other	21.7	2.5
5	Major lung diseases (including emphysema)	26.1	3.0
6	Pneumonia and influenza	23.7	*2.7
7	Diabetes	15.2	1.7
8	Chronic liver disease and cirrhosis	12.9	1.5
9	Atherosclerosis (hardening of the arteries)	12.5	1.4
10	Suicide	12.3	1.4

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* Infectious diseases are not grouped together like heart diseases and cancer are. Centers for Disease Control experts say that as a group, infectious diseases are the No. 4 killer.

STATEMENT OF CHRISTINE STEVENS, SECRETARY, SOCIETY FOR ANIMAL PROTECTIVE LEGISLATION

Recent research developments make it essential that appropriations for the National Institutes of Health and related agencies be thoroughly scrutinized so that scarce funds are not directed to unproductive work.

Widespread concern has been expressed by the public on unnecessary use of animals in which the animals suffer severe pain and distress. Toxicity testing has been a major focus of this concern, and rightly so because very large numbers of animals are used, and the newest scientific work indicates that in many cases the use is not justified. Indeed, a recent paper by David Salsburg indicates that the standard animal tests for carcinogenicity may be leading us far from the accurate information we have been led to believe comes from these tests. I would submit a copy of his paper, "The Lifetime Feeding Study in Mice and Rats - An Examination of Its Validity as a Bioassay for Human Carcinogens," for the use of this distinguished Committee.

Dr. Salsburg describes standard practice in determining the sensitivity and specificity of an assay. He then states: "The author has surveyed the published literature and can find no evidence that the 'definitive bioassay for carcinogenesis' was ever subjected to such validation. The design of this bioassay appears to have been created out of the best thoughts of several committees and reflects the opinions of the committee members."

Giving statistics, he concludes: "Thus the lifetime feeding study in mice and rats appears to have less than a 50% probability of finding known human carcinogens. On the basis of probability theory, we would have been better off to toss a coin." Perhaps most bizarre of all are the decision rules which show that "10% to 70% of the assays produce contradictory answers." At the end of his paper, Dr. Salsburg summarizes: "Presently the lifetime feeding study pre-empts the field. As long as it is considered to be useful in detecting human carcinogens this very expensive and time-consuming procedure will continue to drain the toxicological resources of society. This report questions its usefullness and suggests that it is time to seriously consider alternatives."

At the present time, a large proportion of the funding for the National Toxicology Program continues to go into these standard animal tests. Nobel Laureate Dr. Joshua Lederberg has long urged that greater emphasis be placed on research to develop more accurate alternative short-term tests which should form the chief goal of the more than sixty million dollars appropriated for use in the National Toxicology Program. At present, 40% of the National Toxicology Program budget is devoted to the National Cancer Institute/National Toxicology Program bioassay activity. A bioassay generally costs $400,000 to $500,000 and takes 3½ years to complete. To quote Dr. Lederberg: "Right now there is almost no rationale for deciding whether the mouse, the rat, the rabbit, the guinea-pig or the monkey is going to be the better model for effects on human behavior . . . The one or two or three hundred million dollars a year that we're now spending on routine animal tests are almost worthless from the point of view of standard-setting . . . It is simply not possible with all the animals in the world to go through new chemicals in the blind way that we have at the present time, and reach credible conclusions about the hazards to human health. We are at an impasse. It is one that has deep scientific roots and we had better do something about it."

Even with relatively small funding for the development of alternatives, a committee of the National Research Council has found that they are in many cases superior to animal tests. According to Science magazine 25 February 1983: "In the testing of chemical mutagens 'There has been spectacular progress in developing short term tests that use microorganisms and mammalian cell cultures,' stated the report, Identifying and Estimating the Genetic Impact of Chemical Mutagens. 'These tests are sensitive, efficient, reproducible, and inexpensive.'"

According to the National Research Council press release, "It is neither necessary nor feasible to use mammals for initial screening," the committee told the U. S. Environmental Protection Agency (EPA). Tests with bacteria can be completed in a few days, and tests with mammalian cells in culture require only a few weeks, the committee pointed out. Mouse tests are not only much more expensive, but require several months. With some 70,000 man-made chemicals in commercial use, "it is important to have several rapid, sensitive, inexpensive tests available," the committee concluded.

It should not be assumed, however, that alternatives can be rapidly found for all current use of laboratory animals. Animals will certainly continue to be used in the foreseeable future, but there are many cases in which smaller numbers of animals in more carefully thought out research and under improved conditions of care and treatment would provide better and more productive scientific results.

Currently considerable criticism is being leveled at the Primate Centers, and though the Society for Animal Protective Legislation is not a part of the "Mobilization," we agree that this is an area which should be carefully scrutinized by the Congress with a view to preventing unnecessary animal use and unnecessarily heavy expenditure of government funds. In some cases, excessively cruel experiments have continued over long periods of time. The much-publicized experiments with baby monkeys, putting them in what the experimenters designated as "wells of despair" and developing severe psychological trauma, raise both ethical and economic questions.

There was a review of the Primate Centers' program in 1976 when NIH's Division of Research Resources was reviewed by the firm of Bolt-Beranek, which set up a panel to evaluate the Primate Centers. This review was critical of the quality of research being conducted at the Primate Centers and especially of its core researchers and recommended a thorough review of the Centers. This second review was also critical of the quality of scientists at the Centers. It would seem that this distinguished Subcommittee would wish to examine with care the criticisms and seek to establish what follow-up has been conducted by NIH.

At a time when government funds are tight, any unnecessary experimentation using primates should be brought to an end. Later this month the Convention on International Trade in Endangered Species of Wild Fauna and Flora is meeting in Botswana. All primate species are listed on either Appendix I or Appendix II because of the severe depletion which has taken place in the past few years. Thus the use of primates for research purposes should be restricted to first-class projects lest inferior projects further deplete species that in the future could become totally unavailable or even extinct. Both for humane reasons in the treatment of these highly intelligent and sensitive animals and with a view to enlightened self-interest for future research, the Primate Centers need especially thorough scrutiny by the Appropriations Committee.

The 1976 panel recommended that NIH support research to seek suitable substitutes for primates. We would urge, Mr. Chairman, that you request full details on what has been done to meet this sensible recommendation. We believe that research to develop alternatives, not only for primates but for other animals, too, has been treated as a minor consideration and that it deserves major consideration for the following reasons: (1) to reduce animal suffering; (2) to better protect human health; (3) to reduce government expenditures on research and testing; and (4) to prevent threats to individual species.

STATEMENT OF THOMAS J. KENNEDY, JR., M.D., DIRECTOR, POLICY AND PLANNING, ASSOCIATION OF AMERICAN MEDICAL COLLEGES

Senator PROXMIRE. Our next witness is Dr. Thomas Kennedy. Dr. Kennedy is the director of the Policy and Planning Association of American Medical Colleges.

Dr. Kennedy, it's nice to see you, sir.

Dr. KENNEDY. It's nice to be here, Mr. Chairman.

The Association of American Medical Colleges is the national voice for the Nation's 127 accredited medical schools, their administrations, faculties, students, and teaching hospitals.

Of the three highest priorities to which the constituency of the association is committed, two—biomedical and behavioral research and student financial assistance—are directly relevant to the appropriations bill before before this committee.

PREPARED STATEMENT

Thus, we deeply appreciate the opportunity to present our views to you and respectfully request that the longer statement of them be included in the hearing record.

Senator PROXMIRE. Without objection, that will be done.

[The statement follows:]

STATEMENT OF THOMAS J. KENNEDY, JR., M.D.

Mr. Chairman and members of the Committee, the Association of American Medical Colleges, the national voice for the nation's 127 operating medical schools that speaks on behalf of their administrators, faculties, students and over 400 teaching hospitals, deeply appreciates the opportunity to present its views to the Committee on the appropriations bill for Health, Education and Labor. Of the three highest priorities that the constituency of the Association adopted several years ago and only recently reaffirmed, two---biomedical and behavioral research and student financial assistance---are deeply involved in this legislation.

Research

The National Institutes of Health

It is a great honor and priviledge to be able to appear today before this Committee. The reason is quite simple. In our view, *the single* finest institution operating within the Federal government is the National Institutes of Health (NIH). To a very substantial degree, that agency and its programs have been created and sustained by this Committee and its counterpart in the House of Representatives. These two committees, for almost four decades, have had the consistent vision to recognize the enormous power of modern bioscience to improve the health of the American people. More importantly, they have had the courage, determination and legislative skill to sustain the steady flow of funds that made it possible to convert their vision into reality. Their steadfast commitment to the scientific attack on disease, disability and premature death has been hard-headed, intelligent, generous, unselfish and unpartisan.

The Association's constituents have had the great good fortune over the last 35 years to have worked with the NIH in carrying out your mandates and to have shared with that agency the satisfaction of having enormously improved the health and extended the useful life-span of the people of this country and the whole world. The essence of the Association's appeal to you is to continue your tradition of preserving and expanding the highly productive research activities of the NIH as well as those of its sister agency, the Alcohol, Drug Abuse and Mental Health Administration (ADAMHA).

The President's request of $4.077 billion for the NIH in the FY 1984 budget reflects an increase of less than 2 percent over FY 1983. The Administration's January submission indicated that the proposed level would support about 3700 competing research project grants, a not surprising outcome of so small an aggregate increase. The immediate consternation created by this proposal quickly convinced the Administration that the budget request would have to be revised to permit funding of at least 5,000 competing awards. Unfortunately, however, the decision on how to achieve this highly desirable objective was not to add new funds but rather to transfer funds from other extremely valuable programs within the NIH. Reductions totaling $141 million were made in noncompeting research project grants, center grants, biomedical research support grants, other types of research grants, research contracts for clinical trials, intramural research, direct operations and buildings/facilities. Even these severe measures did not yield sufficient money to *fully* fund 5,000 competing grants, and further staff negotiations to decrease awards to levels below those recommended by study sections are expected to be necessary. Meanwhile, serious imbalances have been induced in the NIH portfolio of mechanisms for attacking critical problems of disease. The research center program has been particularly crippled not only for FY 1984, but for a long time thereafter; and very serious problems have been created for the academic institutions that host these centers.

After careful analysis, the AAMC has joined 119 other concerned organizations in a recommendation that $487 million be added to the FY 1983 appropriation to once again make the NIH whole. This addition would:

- Fully fund the average number of new and competing renewal research grants awarded over the last five years, with a resulting award rate of about 35%;

- Support approximately 10,000 research trainees, about the average number of the past five years;

- Eliminate arbitrary reductions, initially imposed in FY 1982 and FY 1983 and carried forward into the FY 1984 proposals, in the direct and indirect costs of most research grant programs;

- Restore the recently proposed reductions in center grants, in biomedical research support grants, in other research grants programs and in research contracts for clinical trials to the levels requested by the President last January;

- Provide $33 million---less than 1% of the budget---for modest but *real* growth; about $8 million of this would be specifically earmarked for expanding the President's initiative to upgrade laboratory instruments and equipment.

The President's policy initiative embodied in the FY 1984 budget to expand national investments in basic scientific research, dramatically reflected in the budgets of the National Science Foundation and the Department of Defense, is conspicuously absent from the NIH budget. The putative basis for this exception is that the NIH has been generously supported in the past. The truth of the matter is quite different. Measured in constant dollars, that is, in the real purchasing power of the money, the appropriations for the NIH peaked in FY 1979, fell at an average rate of 4% per year in FYs 1980, 1981 and 1982, held at about the FY 1982 level in FY 1983 and will resume their downward drift in 1984, if the amounts proposed in the President's budget are approved.

Past investments in biomedical and behavioral research have yielded a cornucopia of benefits; expectations for even greater achievements are burgeoning, not shrinking. The payoff has not only been in a healthier America but a great variety of indirect benefits to the economy. A recent analysis claims that for each public dollar invested, $13 in benefits has been accrued. Congressional foresight and generosity, the brains and know-how of American scientists and a superb group of research-intensive universities have propelled the U.S. to world preeminance in science in general and in biomedical science in particular.

But stop-and-go funding, and static or eroding budgets do not create the milieu in which scientists or the academic infrastructure for science thrive. The Association hopes that the Committee will recognize this reality and take appropriate action.

The National Library of Medicine. Two recently published studies by the AAMC, one for the National Library of Medicine, have opened wide vistas of opportunity for advances in the exploitation of information management technology to improve the clinical care of the sick. A modest additional investment of $3 million in the Computers in Medicine Program of the NLM, in the opinion of the Association, would yield a spectacular return.

The Alcohol, Drug Abuse and Mental Health Administration (ADAMHA)

The President's proposal for the ADAMHA eliminates clinical training funds in the NIMH while providing approximately equivalent increases in the ADAMHA research programs. While the AAMC applauds the research budget proposed, it believes that the Nation will have paid a high price for it, unless clinical training funds are restored. These are badly needed to increase the number of physicians capable of exploiting in their practices the new knowledge and insights of biological psychiatry.

Student Assistance

The rising costs of medical education, which the medical schools resisted passing on to students for many years, have recently forced tuition increases, while inflation has sharply escalated living expenses of students. Federal loan and scholarship money, the overwhelmingly major source of assistance to medical students, is absolutely essential if any but the progeny of affluent families are to be educated for the profession.

The student assistance programs administered by the Health Resources and Services Administration (HRSA), terminally ill for the last several years, are scheduled to succumb in FY 1984. The Administration is not even willing to guarantee Health Educational Assistance Loans (HEAL) at their authorized credit ceiling. The AAMC recommends: that new capital of $20 million be provided for the Health Professions Student Loan (HPSL) revolving fund; that the program of Scholarships for Students in Exceptional Financial Need be funded at the level of $6 million; and that the Administration be instructed to guarantee HEAL loans up to the level authorized in the enabling statute.

The largest single genre of financial assistance to medical students is, of course, the Guaranteed Student Loan (GSL). Further restrictions on this invaluable program would severely limit the access to medical education of economically disadvantaged students.

Medical Education Assistance

The last vestiges of the bold Federal initiative of two decades ago to increase the country's stock of physicians are budgeted under the health professions special project activities of the HRSA. The Association is convinced that the need for training funds to enhance the number and the quality of primary care physicians continues to be greater than the Administration has requested and would urge increments of 20% be added to the amounts requested for activities related to family medicine, general internal medicine and area health education centers.

Health Planning

Even though only the House of Representatives passed the required legislation, the 96th Congress demonstrated strong bipartisan support for a national health planning program to monitor capital expenditures as a cost-containment device. The AAMC recommends that funding of the existing health planning program be continued at a level of at least $68.7 million in FY 1984.

In summary, the Association of American Medical Colleges urges the Committee to add to the funds requested by the President for programs in biomedical and behavioral research, medical information management, student financial assistance, health professions education and health planning. If further explication of the Association's views on these matters is needed, by all means request the desired information.

Dr. KENNEDY. First, biomedical and behavioral research. The President's pending request for the NIH reflects an increase over last year of less than 2 percent. The administration's January submission was severely criticized for including funds for only about 3,700 competing research project grants. The recently proposed remedy adds no new funds but only rearranges the amounts proposed in January, thereby truncating virtually all other NIH programs. This solution is not satisfactory.

After careful analysis, the AAMC has joined 119 other concerned organizations in a recommendation that $487 million be added to the fiscal year 1983 appropriation to once again make the NIH whole.

Our alternative budget would:

First, fund 35 percent of all eligible competing project grants. just a few more than 5,000;

Second, restore all earlier arbitrary reduction in direct and indirect costs that have been carried forward into the April proposal;-

Third, support approximately 10,000 research trainees;

Fourth, restore funds for center grants, biomedical research support grants, research contracts for clinical trials, and other research programs to the levels requested in January 1983; and

Fifth, provide $33 million for modest real growth.

The President's budget proposal provides significant increases for ADAMHA research programs, while eliminating clinical training in NIMH. The AAMC applauds the research expenditures proposed, but believes that the Nation will have paid a high price for them unless clinical training funds are restored. These are badly needed to train physicians to exploit in their practices the new knowledge and insights of biological psychiatry.

On the question of student assistance, in the face of rising tuitions for medical education, Federal loan and scholarship money is absolutely essential if any but students from affluent families are to be educated for the profession.

The student assistance programs administered by the Health Resources and Services Administration have been terminally ill for the last several years and are scheduled to succumb in 1984.

Aternatively, the AAMC recommends: First, that new capital of $20 million be provided for the HPSL loan fund; second, that the programs for scholarships for students in exceptional financial need be funded at the level of $6 million; third, that that the administration be instructed to guarantee HEAL loans up to the levels authorized in the enabling statute; and fourth, that the Congress resist further restrictions on the guaranteed student loan program, the largest single source of aid to medical students.

In the area of medical education, little remains of the bold Federal initiative of two decades ago to increase the country's stock of physicians. The association is convinced, however, that the need for training funds to enhance the number and quality of primary care physicians continues to be greater than the adminstration has requested and would urge that increments of 20 percent, or about $12 million, be added to the amounts requested for primary care training programs, including area health education centers.

Finally, in the matter of health planning, even though only the House passed the required legislation in the 97th Congress, strong bipartisan support for a national health planning program to monitor capital expenditures as a cost-containment device was demonstrated. The AAMC recommends that funding of the existing health planning program be continued at the level of $69 million for fiscal year 1984.

Thank you very much.

Senator PROXMIRE. Thank you, Dr. Kennedy, very much. We appreciate your statement.

STATEMENT OF PEYTON E. WEARY, M.D., ON BEHALF OF THE AMERICAN ACADEMY OF DERMATOLOGY AND THE SOCIETY FOR INVESTIGATIVE DERMATOLOGY

Senator PROXMIRE. Our next witness is Dr. Peyton Weary, Washington representative, American Academy of Dermatology.

Dr. Weary, go right ahead, sir.

Dr. WEARY. Thank you, Senator.

I'm presenting this testimony on behalf of the American Academy of Dermatology and the Society for Investigative Dermatology.

PREPARED STATEMENT

We have submitted, for the record, testimony in regard to a number of different institutes, and I will not go through that.

[The statement follows:]

STATEMENT OF PEYTON E. WEARY, M.D.

Mr. Chairman, I am Peyton E. Weary, M.D., Chairman of the Department of Dermatology at the University of Virginia School of Medicine and Washington Representative from the Council on Governmental Liaison of The American Academy of Dermatology. I am presenting this testimony on behalf of The American Academy of Dermatology, whose membership of over 6,000 represents the majority of American Dermatologists, and on behalf of The Society for Investigative Dermatology, the representative organization for the dermatologic biomedical research community.

We are entering a most exciting and productive era of dermatologic research which has come about largely as a result of funds granted by the Congress to The National Institutes of Health for support of both extramural and intramural basic research. We are, indeed, grateful to the Congress for its continuing strong support for the National Institutes of Health in the face of so many worthwhile competing health care programs.

Two years ago, I reported to this committee that a very promising group of compounds were under investigation at the NIH and elsewhere. These compounds called synthetic retinoids are derivatives of vitamin A. They produce marked changes in the outer layers of the skin among other effects, and they appear to be useful for a number of disorders including acne, psoriasis, and a group of inherited disorders characterized by thickening of the outer layers of the skin which we call ichthyosis. I thought you might like to see what one of these remarkable compounds can do after only four months of treatment in severe scarring acne. This drug is now available for prescription use and has provided marked improvement now for many thousands of patients with severe acne in the last nine months. In the long run it will substantially reduce the health care costs for this unfortunate condition. This, then, provides a splendid example of how basic research has been rapidly translated into improved patient care and can reduce health care costs.

A number of other developments in dermatologic research show promise of improving the diagnosis and management of many chronic dermatologic diseases. We anticipate that the update of the report on Research Needs and Priorities in Dermatology which the Congress called for last year will be completed by the end of this year and will detail these major advances for you.

Mr. Chairman, we have repeatedly emphasized in our prior testimony before this committee the fact that research in skin diseases is a shared responsibility of a number of institutes. We are particularly pleased to note that the Congress has acknowledged that fact by calling for the creation of an interagency coordinating committee in the proposed legislation which would create a new Institute of Arthritis, Musculoskeletal and Skin Disease. I would like in the remainder of this testimony to direct your attention to specific institutes which share the responsibility for supporting skin-related research.

1. The National Institute of Arthritis, Diabetes, Digestive and Kidney Diseases

This institute which supports the largest segment of skin-related research is once again threatened with inadequate support in the President's proposed budget. You have already heard testimony from other members of an NIADDK coalition recommending substantial increases for this institute over and above the proposed budget, and we also endorse this increased support to a level of 475 million dollars. We would also request that the Congress specifically call for a 10% increase in support for skin-related research within this institute to ensure that the initiatives I noted earlier in such diseases as psoriasis, ichthyosis, and acne are actively pursued.

2. The National Institute of Allergy and Infectious Diseases

At this time, this institute remains the most underfunded institute at the N.I.H. The percentage of approved grants which are funded is unacceptably low. This situation has persisted now for some years and is much in need of corrective action. The whole field of allergy and immunology is replete with exciting new opportunities which will impact upon the interests of a number of other institutes. There are still dread diseases such as the acquired immunodeficiency syndrome (AIDS) which require determined research efforts. The dermatologic community is particularly concerned about this syndrome because of the malignant skin lesions which are a major finding in this condition. Dermatologists were among the first to identify and call attention to this disease. Because much skin disease is related to allergy, immunology, and infections, we are acutely aware of the need to capitalize upon the significant new opportunities for research in the diseases for which this institute has major responsibility. We, therefore, urge a substantial increase in support for this institute well above a cost-of-living increase to restore reasonable parity in percentage of approved grants which are funded in comparison with other comparable institutes.

3. The National Cancer Institute

We are pleased that a renewed interest in malignant melanoma has been generated at the request of the Congress. We would point out that the intramural dermatology program in The Cancer Institute is a shining example of how extremely competent and productive intramural research can stimulate major advances in a discipline. At present very exciting research is underway in this program on genetically induced cancer as an example. We would emphasize the importance of the dermatology intramural program in training a large number of capable young research scientists. We would ask that the Congress acknowledge this fact by calling for an orderly expansion of this fine intramural program.

4. The National Institute on Aging

We are, frankly, disappointed that there has not been more support by this institute for studies related to problems of the skin. At present, less than 1% of this institute's budget is devoted to studies of the skin. When we consider that twelve percent of Americans are over the age of 65 and that approximately 60 percent have one or more skin problems-- many related to the aging process which reduces wound healing and disturbs both the inflammatory and immune responses. Such alterations in turn lead to such common and costly problems as chronic bed sores. It is thus extremely disappointing to find problems such as these not being addressed. We would urge the Congress to direct the new leadership of the institute to acknowledge the importance of skin related research and to encourage and fund research programs which:

1. Provide more information about age-associated functional changes in normal skin.
2. Address the impact of aging upon the risk and course of diseases of the skin and treatment for common age-related diseases of the skin.
3. Search for possible new preventive or therapeutic measures to combat the burden of dermatologic disease in the elderly.

5. The National Institute for Occupational Safety and Health

The National Institute for Occupational Safety and Health (NIOSH) has stated that the most pervasive current occupational health problem in the United States is widespread, debilitating occupationally related skin disorders. Accordingly, then, we are pleased that the Congress called last year for continued emphasis on occupational skin disease research. However, we continue to be concerned about substantial reductions in the level of funding for this institute. NIOSH has sustained budget cuts far exceeding those of any NIH institute proportionately. We have repeatedly stressed the economic and social burden of occupational skin disease upon our society and the need for increased support for research in this important area which accounts for 45 percent of all occupational illness. Unless the institute receives more support, however, such research simply cannot be funded. There is no shortage of good grant requests, only of funds to support them. We would urge the restoration of adequate funds to this institute, and we would suggest that unless this is accomplished promptly the demoralizing effects of yearly reductions in funding will severely compromise the ability of this institute to accomplish its research and development mission. We would specifically request the Congress to provide funds for NIOSH to:

a.) Continue the efforts begun in 1981 to support occupational skin research by targeting funds for that purpose

b.) Actively recruit and hire an occupational dermatologist to head up and coordinate a sustained program of research, training and prevention in the field of occupational skin disorders

c.) Prepare an update of their 1979 and 1981 reports on occupational skin disease

We request the opportunity to submit at a later time additional information to support our requests.

6. The National Institute of Environmental Health Sciences

The major interface of man and his environment is the skin. Many noxious environmental agents injure the skin of man. The skin, for example, is subject to injury from a wide range of toxic chemical, physical, and biologic agents including sunlight and extremes of dryness and humidity. We believe the opportunities for productive research are many, and we would urge this institute to maintain an identifiable program to stimulate research on the health effects of environmental skin injury.

Thank you, Mr. Chairman, for the opportunity to present our concerns and suggestions.

Dr. **Weary**. But in the testimony that I have submitted, I have noted the fact that a whole new group of compounds has been developed in recent years called retinoids.

These compounds are opening up substantial new frontiers in treatment and research in dermatology.

It's not often that we have an opportunity to show the Members of Congress the fruits of their labor, and I thought that I would bring with me some photographs of some patients who underwent a clinical trial with this drug in our institution last year, and this drug is now available and on the market for treating acne.

These photographs are before and after photographs taken after 4 months of treatment with this drug. And I will show you four patients.

On the right, are the photographs before. And on the left, the photographs after 4 months of treatment.

To show the tremendous improvement that has resulted from the use of this drug in these very unfortunate individuals with severe cystic acne.

The initial pioneering studies for this drug were conducted at the Clinical Center at the NIH, and a number of studies are continuing on this drug, not only for acne but for other disorders, such as psoriasis and various karytinizing disorders which afflict many millions of Americans.

This is an important group of compounds, and the studies that are continuing are being supported also in large measure by the NIH funds. In fact, there will be papers presented at the Society of Investigative Dermatology meeting this week, one of which is from our own department, on continuing studies on this drug. And these studies are supported by the NIH.

I would point out to you, Senator, that this is a very good example of how the money that is committed to biomedical research can be translated into improved patient care and also how this is a very cost-effective type of device, because treatment of these patients would oftentimes continue many years at costs that number thousands of dollars for the very severe cystic acne patients.

And here with a drug that promises great improvement in a very short period of time at a much reduced cost, we can see how the funds can be translated into a cost-benefit situation.

I would also like to comment about one other institute, one institute in particular that we mentioned in our testimony, and that is the National Institute for Occupational Safety and Health.

Senator Proxmire, we have a particular concern about this, because 45 percent of all occupational illness is dermatologically related, and it accounts for 25 percent of lost man-hours from work. And we have repeatedly pointed this out to the Congress, and the Congress, in response, has been very kind in issuing a mandate to this Institute to support and fund research projects.

There have been a number of very good grants that have been submitted and have been funded. But unfortunately this Institute is suffering from a very severe financial loss over the years. Gradually, research support has been eroded in this Institute to the point where the grants are available but the funds are not available to support them.

We feel that this, in particular, is a critical situation. We feel that further erosion of the support for this Institute is going to be detrimental.

And again, I would point out to you that there's probably no better example of how research to reduce the burden of illness in the population can result in substantial savings to society, because these people, when they are afflicted with diseases, are unable to work and unable to be productive, and this is a loss to our society which I think we can ill afford.

That concludes my testimony. I'll be glad to answer any questions you may have.

Senator PROXMIRE. Thank you very much.

You say, with respect to the National Institute of Allergy and Infectious Diseases, that the Institute remains the most underfunded institute at the NIH. This is as a percentage of approved grants which are funded?

Dr. WEARY. Yes; in terms of percentage of approved grants. That is my understanding.

I believe that the pay lines were much lower than any other institute, around 150 was the last that I remember, which is much lower than any other institute, which means that percentage of approved grants are substantially lower than for other institutes.

And I think this is a very severe problem, particularly since there are so many new, exciting opportunities in immunology, particularly since some of the diseases that are threatening our society, such as the acquired immune deficiency syndrome, are largely coming under the mandate of this Institute.

And I think that this is something that needs to be substantially corrected.

Senator PROXMIRE. Thank you very much, Dr. Weary.

Dr. WEARY. Thank you, sir.

Senator PROXMIRE. We very much appreciate your presentation. What was the period of time for these photographs.

Dr. WEARY. Four months.

Senator PROXMIRE. Four months in each case?

Dr. WEARY. Yes.

Senator PROXMIRE. That's remarkable.

Dr. WEARY. It's a remarkable improvement.

STATEMENT OF SAMUEL O. THIER, M.D., PROFESSOR AND CHAIRMAN, DEPARTMENT OF MEDICINE, YALE UNIVERSITY SCHOOL OF MEDICINE, ON BEHALF OF THE ASSOCIATION OF PROFESSORS OF MEDICINE

Senator PROXMIRE. Our next witness is Dr. Samuel Thier, chairman of the department of medicine, Yale University, Association of Professors of Medicine.

Dr. THIER. Thank you, Senator Proxmire.

My testimony is on behalf of the Association of Professors of Medicine, the organization that represents the chairmen of the departments of internal medicine in the 127 U.S. medical schools.

We appreciate the opportunity to share our views concerning the fiscal year 1984 budget for the NIH. The funding for the NIH is of great importance to the professors of medicine because we are physicians and scientists and because we chair the departments in which the majority of extramural clinical research is conducted.

Since World War II, the Federal Government has been the primary source of support for biomedical research. The wisdom of this public investment is indisputable when one examines the major achievements of the past three decades.

The discovery of vaccines against polio, rubella, improved treatment of cancer and cardiovascular disease, and the development of transplantation procedures are just a few examples of the myriad innovations that have revolutionized the practice of medicine and allowed millions to enjoy longer and healthier lives.

With adequate support, this prolific period of bioscientific discovery is certain to be continued. I realize that members of this subcommittee are frequently told that we are experiencing a virtual explosion of knowledge in the biosciences, but this is not mere hyperbole.

The ability to analyze the genetics of a cell is leading to the development of treatments for hereditary diseases. Further study of the oncogenes is expected to yield important information regarding the cause and treatment of cancer. The discovery of monoclonal antibodies has great potential for improving the treatment of multiple sclerosis, juvenile diabetes mellitus, and many rheumatic conditions.

The importance of these basic science discoveries simply cannot be overstated. Now, more than ever before, the biomedical research community must be able to seize the scientific opportunity and expand upon recent discovery.

Ironically, it's at this point that the administration proposes what would be the smallest percentage budgetary increase in the history of the NIH. Against a background of double-digit increases for research and development in other agencies. the NIH would receive a mere 1.8-percent increase. We find this incomprehensible—not only because of the potential loss of scientific opportunity. We also fail to understand why the administration's priorities for Federal research and development are so clearly at odds with those of the American public. A study by the National Science Foundation revealed that the Americans consider bioscience to be the No. 1 Federal research priority, while defense research was ranked fifth. Yet, the administration's fiscal 1984 budget proposes $6.9 billion, or a 29-percent increase for the Department of Defense research and development, 16 times the percentage increase for the NIH and, in fact, an increase that is, in absolute dollars, almost twice that of the absolute budget of the entire NIH. Certainly, defense R&D is important. However, in the view of the Association of Professors of Medicine, research into the diagnosis, treatment, and prevention of human disease also merits a significant share of Federal R&D spending.

Members of this subcommittee have received a statement entitled "Health Research: A Proposal for fiscal year 1984," a document endorsed by the professors of medicine at over 115 other organizations. It advocates an additional $487 million for the NIH over the fiscal year 1983 budget. This 12-percent increase would allow for funding of just over 5,000 new and competing renewal grants, 10,000 research trainees, full reimbursement to institutions of indirect costs associated with research, and improved instrumentation. It would allow for modest but badly needed growth in all NIH programs, including research centers, contracts, and new clinical trials. For the past decade, the NIH has been in an essentially no-growth phase, and there has, in fact, been a steady decline in terms of constant dollars since 1979.

I'd like to emphasize that this document demonstrates the research community's commitment to all of the programs of the NIH. In the past, efforts have been made to assure funding for at least 5,000 new and competing renewal grants, a minimally acceptable level if the stability of the investigator-initiated is to be assured.

The APM continues to place the highest priority on funding for these awards, which are the foundation of our Nation's research effort and hold the greatest promise for important discoveries. However, in recent years, within the limits of the resources available, the support of 5,000 first-year grants has been accomplished only at the expense of other NIH programs. An increasing percentage of the NIH budget has had to be devoted to extramural programs. In fact, NIH officials estimate that if this shifting of resources continues at the current rate, extramural research will represent 100 percent of the NIH budget by 1993, and Peter is being robbed to pay Paul.

The distinguished chairman of this subcommitee has accurately described this reallocation of funds as "sleight of hand," and we urge that it not be tolerated by the Congress. Appropriation of an additional $487 million would provide the essential support for at least the 5,000 new and competing grants as well as stable funding for all of the other NIH programs.

In summary, the adoption of the administration's fiscal year 1984 budget for NIH would threaten the continued success of our Nation's biomedical research effort. In addition to lost scientific opportunities, inadequate funding is alienating young physicians from research careers. As in the past, it is to the Congress that we look for support. An article in the April 8 issue of Science magazine stated that the Office of Management and Budget has proposed such a small increase for NIH "because it expected Congress to increase that budget anyway." The Association of Professors in Medicine only hopes that this assumption was correct and that, once again, the Congress will champion the NIH cause. Only your strong advocacy can assure that the continued vigor of the biomedical research effort will go on.

Thank you for your attention.

I'll be happy to answer any questions.

Senator PROXMIRE. Thank you very much, Dr. Thier.

Doctor, at the top of page 2 of your prepared testimony, you say "The discovery of monocolonal antibodies has great potential for improving therapies for multiple sclerosis," among other things.

What does that really mean? I have a personal interest in that disease. My sister died of multiple sclerosis. She had it for 25 years. Although my father was a doctor it was the most frustrating experience that you can imagine, because there just didn't seem to be anything that anybody had done about multiple sclerosis for 100 years. No progress had been made, none. There'd be remissions, but no real assurance that the disease could be cured or anything of the kind. Has there been a breakthrough here? She died 15 years ago, so there might well have been.

Dr. THIER. I certainly don't mean to imply that there is on the horizon a cure. Now, for the first time, in the last year there's been a report in which controlled data suggest that immunologic, anti-immune therapy has been beneficial to patients with multiple sclerosis, giving more credence to the possibility that there is an immune basis to the disease.

Senator PROXMIRE. The problem is that so often when they'd come in with treatments that did seem quite promising, the remissions were so frequent with people with multiple sclerosis, that it was hard to tell whether the treatment was really working or whether it was a remission that would have occurred even if nothing had been done.

Dr. THIER. That's true. And that was the excitement of the controlled trial where there at least was a comparison of what the rate of remission was in a comparable population. I think the hope is that if one can really have immune therapy do something, the use of monoclonal antibodies would be a much less toxic form of immune therapy than would the immunosuppressive agents that we're using.

Senator PROXMIRE. I see.

Dr. THIER. This is obviously theoretical at this point.

Senator PROXMIRE. Very good. Thank you very much, sir. I certainly appreciate it. I wish again—with all these superb witnesses, I wish we had more time for questions, but we just don't have it.

Dr. THIER. Thank you.

Senator PROXMIRE. Your statement will be included at this point.

[The statement follows:]

STATEMENT OF SAMUEL O. THIER, M.D.

I AM DR. SAMUEL O. THIER, PROFESSOR AND CHAIRMAN OF THE DEPARTMENT OF INTERNAL MEDICINE AT THE YALE UNIVERSITY SCHOOL OF MEDICINE. MY TESTIMONY IS ON BEHALF OF THE ASSOCIATION OF PROFESSORS OF MEDICINE (APM), THE ORGANIZATION THAT REPRESENTS THE CHAIRMEN OF DEPARTMENTS OF INTERNAL MEDICINE IN THE 127 U.S. MEDICAL SCHOOLS. WE APPRECIATE THIS OPPORTUNITY TO SHARE OUR VIEWS REGARDING THE FY 1984 BUDGET FOR THE NATIONAL INSTITUTES OF HEALTH (NIH). FUNDING FOR NIH IS OF GREAT IMPORTANCE TO THE MEMBERS OF APM BECAUSE WE ARE PHYSICIAN SCIENTISTS AND BECAUSE THE MAJORITY OF EXTRAMURAL CLINICAL RESEARCH SPONSORED BY THE NIH IS CONDUCTED IN THE DEPARTMENTS WE CHAIR.

SINCE WORLD WAR II, THE FEDERAL GOVERNMENT HAS BEEN THE PRIMARY SOURCE OF SUPPORT FOR BIOMEDICAL RESEARCH. THE WISDOM OF THIS PUBLIC INVESTMENT IS INDISPUTABLE WHEN ONE EXAMINES THE MAJOR ACHIEVEMENTS OF THE PAST 3 DECADES. THE DISCOVERY OF VACCINES AGAINST POLIO AND RUBELLA, IMPROVED TREATMENT FOR CANCER AND CARDIOVASCULAR DISEASE, AND THE DEVELOPMENT OF TRANSPLANTATION PROCEDURES ARE JUST A FEW EXAMPLES OF THE MYRIAD INNOVATIONS WHICH HAVE REVOLUTIONIZED THE PRACTICE OF MEDICINE AND ALLOWED MILLIONS TO ENJOY LONGER, HEALTHIER LIVES. WITH ADEQUATE SUPPORT, THIS PROLIFIC PERIOD OF BIOSCIENTIFIC DISCOVERY IS CERTAIN TO BE CONTINUED. I REALIZE THAT MEMBERS OF THIS SUBCOMMITTEE ARE FREQUENTLY TOLD THAT WE ARE EXPERIENCING A VIRTUAL EXPLOSION OF KNOWLEDGE IN THE BIOSCIENCES. THIS IS NOT MERE HYPERBOLE! THE ABILITY TO ANALYZE THE GENETICS OF A CELL IS LEADING TO THE DEVELOPMENT OF TREATMENTS FOR MANY HEREDITARY DISEASES. FURTHER STUDY OF ONCOGENES IS EXPECTED TO YIELD IMPORTANT INFORMATION REGARDING THE CAUSE AND TREATMENT OF CANCER. THE DISCOVERY OF MONOCLONAL ANTIBODIES HAS GREAT POTENTIAL FOR IMPROVING THERAPIES FOR MULTIPLE SCLEROSIS, JUVENILE DIABETES MELLITUS, AND MANY RHEUMATIC CONDITIONS. THE IMPORTANCE OF THESE BASIC SCIENCE DISCOVERIES SIMPLY CANNOT BE OVERSTATED. NOW, MORE THAN EVER BEFORE, THE BIOMEDICAL RESEARCH COMMUNITY MUST BE ABLE TO SEIZE SCIENTIFIC OPPORTUNITY AND EXPAND UPON RECENT DISCOVERY.

IRONICALLY, IT IS AT THIS POINT THAT THE ADMINISTRATION PROPOSES WHAT WOULD BE ONE OF THE SMALLEST PERCENTAGE BUDGETARY INCREASES IN THE HISTORY OF THE NIH. AGAINST A BACKGROUND OF DOUBLE-DIGIT INCREASES for research and development at other agencies, the NIH would receive a mere 1.8% increase. We find this incomprehensible--not only because of the potential loss of scientific opportunity. We also fail to understand why the Administration's priorities for Federal research and development are so clearly at odds with those of the American people. A study by the National Science Foundation revealed that Americans consider bioscience to be the number one Federal research priority. Defense research was ranked fifth. Yet, the Administration's FY 1984 budget proposes a $6.9 billion (29%) increase for DOD research and development--16 times the increase proposed for NIH and, in fact, almost twice the size of the entire NIH budget. Certainly, defense R & D is important. However, in the view of the Association of Professors of Medicine, research into the diagnosis, treatment and prevention of human disease also merits a significant share of Federal R & D spending.

Members of the Subcommittee have received a statement entitled, "Health Research: A Proposal for FY 1984." This document, which is endorsed by the APM and over 110 other organizations, advocates an additional $487 million for NIH over FY 1983. This 12% increase would allow for funding of just over 5,000 new and competing renewal grants, 10,000 research trainees, full reimbursement to institutions of indirect costs associated with research, and improved instrumentation. It would allow for modest but badly needed growth in all NIH programs including research centers, contracts, and new clinical trials. For the past decade, the NIH has been in an essentially no-growth phase; there has been a steady decline in terms of constant dollars since 1979.

I would like to emphasize that this document demonstrates the research community's commitment to *all* of the programs of the NIH. In the past, efforts have been made to assure funding for *at least* 5,000 new and competing renewal grants (R01s)--*a minimally acceptable* level if the stability of the investigator-initiated project base is to be assured. The APM continues to place the highest priority on funding for these awards which are the foundation of our nation's research effort and hold the greatest promise for important discoveries. However, in recent years, within the limits of the resources available, THE SUPPORT OF 5,000 R01S HAS BEEN ACCOMPLISHED ONLY AT THE EXPENSE OF OTHER NIH PROGRAMS. AN INCREASING PERCENTAGE OF THE NIH BUDGET HAS HAD TO BE DEVOTED TO THE EXTRAMURAL PROGRAM. IN FACT, NIH OFFICIALS ESTIMATE THAT IF THIS SHIFTING OF RESOURCES CONTINUES AT THE CURRENT RATE, EXTRAMURAL RESEARCH WILL REPRESENT 100% OF THE NIH BUDGET BY 1993. PETER IS BEING ROBBED TO PAY PAUL. THE DISGINGUISHED CHAIRMAN OF THIS SUBCOMMITTEE HAS ACCURATELY DESCRIBED THIS REALLOCATION OF FUNDS AS "SLEIGHT OF HAND" AND WE URGE THAT IT NOT BE TOLERATED BY THE CONGRESS. APPROPRIATION OF AN ADDITIONAL $487 MILLION WOULD PROVIDE THE ESSENTIAL SUPPORT FOR AT LEAST 5,000 R01S AS WELL AS STABLE FUNDING FOR OTHER NIH PROGRAMS.

IN SUMMARY, ADOPTION OF THE ADMINISTRATION'S FY 1984 BUDGET FOR NIH WOULD THREATEN THE CONTINUED SUCCESS OF OUR NATION'S BIOMEDICAL RESEARCH EFFORT. IN ADDITION TO LOST SCIENTIFIC OPPORTUNITIES, INADEQUATE FUNDING IS ALIENATING YOUNG PHYSICIANS FROM RESEARCH CAREERS. AS IN THE PAST, IT IS TO THE CONGRESS THAT WE LOOK FOR SUPPORT. AN ARTICLE IN THE APRIL 8 ISSUE OF SCIENCE MAGAZINE STATED THAT THE OFFICE OF MANAGEMENT AND BUDGET HAD PROPOSED SUCH A SMALL INCREASE FOR NIH "BECAUSE IT EXPECTED CONGRESS TO INCREASE THE BUDGET ANYWAY." THE ASSOCIATION OF PROFESSORS OF MEDICINE ONLY HOPES THAT THIS ASSUMPTION WAS CORRECT AND THAT ONCE AGAIN, THE CONGRESS WILL CHAMPION THE NIH CAUSE. ONLY YOUR STRONG ADVOCACY CAN ASSURE THE CONTINUED VIGOR OF THE BIOMEDICAL RESEARCH EFFORT.

THANK YOU FOR YOUR ATTENTION. I WOULD BE HAPPY TO ANSWER ANY QUESTIONS.

STATEMENT OF DR. ROBERT M. ROSENZWEIG, PRESIDENT OF THE ASSOCIATION OF AMERICAN UNIVERSITIES

Senator PROXMIRE. I understand that instead of Dr. Clodius, we have Dr. Robert Rosenzweig, president of the Association of American Universities, who will testify next.

Dr. Rosenzweig, we are delighted to have you.

Dr. ROSENZWEIG. Thank you, Senator Proxmire.

I'm here this morning on behalf of the Joint Committee on Health Policy of the Association of American Universities, the American Council on Education, and the National Association of Land-Grant Colleges and State Universities.

I have submitted a prepared statement for the record, and in these oral remarks, I want to focus on an issue that I must say I regret deeply that it is necessary to discuss at all, namely, the proposal in the NIH proposal to retreat from the policy of full reimbursement of the costs of research, both direct and indirect.

That proposal is one element of a package of reductions that is designed to provide funding for 5,000 investigator-initiated new and renewal grants, as you've heard already from previous witnesses.

The research universities of the Nation, Mr. Chairman, believe that it is admirable to establish as a goal a minimum of 5,000 such grants each year. We supported that goal when it was set in 1979, and we continue to believe that it is a sensible and realistic estimate of the capacity of the research community. What we don't agree to is the proposition that's enshrined in this budget that this goal takes precedence over all other goals in the conduct of biomedical research and training.

This year, in order to reach the figure of 5,000, the administration proposes to eliminate funding for important research centers, to cut drastically the budget for the biomedical research support grant program and, alone among Government agencies, to depart from the understanding reached after three years of negotiations over the cost principles of OMB Circular A-21.

It seems to us that there are only two ways of dealing with this budget without risking severe damage to the enterprise that constitutes biomedical research and training. The first, and obviously the preferred way, is to appropriate sufficient funds to pay fully for the objective of 5,000 grants. This would amount to an additional appropriation of somewhere between $400 and $500 million. That action would, in our view, be fully justified by the need for research and training and by the prospects for productive use of those funds. This course of action would reject the false proposition that the work of individual scientists can be adequately supported only at the cost of damaging the institutions in which they do their science. We urge that course of action on the committee.

The second possible course of action, if the first is not feasible, is to direct NIH, as in effect it was directed last year by the Congress, to fund fully the number of grants that its appropriation will support or, failing that, to share reductions equitably among the categories of costs, all of which are real and all of which are essential to the health of biomedical research.

Mr. Chairman, last year the Congress directed the Public Health Service to explore, in cooperation with university officials and scientists, what was called the perception that indirect costs have risen at a disproportionate rate. That exploration has not yet taken place. I have attached to remarks a chronology of the events that followed from that injunction to consult. It may be of interest to the committee.

We are prepared to engage in consultation on any aspect of the subject of indirect costs and to follow its results wherever they may lead. We ask the committee's support, and we offer ours.

Thank you, Mr. Chairman.

[The statement follows:]

STATEMENT OF DR. ROBERT M. ROSENZWEIG

Mr. Chairman and members of the Subcommittee, we are testifying this morning in behalf of the Joint Committee on Health Policy of the Association of American Universities, American Council of Education, and the National Association of State Universities and Land-Grant Colleges. In the science departments and medical centers of the institutions comprising these associations, the vast preponderance of academic health training and biomedical research conducted in the United States takes place. Our interest in the deliberations of your Subcommittee regarding appropriation levels for health oriented programs is, therefore, profound.

At these institutions, most of the academic manpower training programs including nursing programs occurs. Similarly, activities dealing with preventive care and treatment are at the core of our health centers. Further, the significant research programs of ADAMHA, the Alcohol, Drug Abuse and Mental Health Administration are deeply entwined in our research programs and training programs. Your Subcommittee this year will graciously provide opportunities to testify to many organizations oriented specifically toward a special concern such as mental health, or nurse training. Through our participation in the Coalition for Health Funding, we are able to voice our concerns and interests. At this time we endorse the position paper the Coalition has submitted to your Subcommittee. We believe that both the funding levels requested and the rational presented for those levels are accurate. In the necessarily limited time available to present our views this morning, we will restrict ourselves entirely to funding for the National Institutes of Health.

Mr. Chairman, NIH enjoys an enviable reputation on Capitol Hill. It begins with a head start over most federal agencies in that the concern for good health ranks uppermost in the minds of most citizens, and the fear of the ravaging effects of disease -- physical, emotional, and financial -- certainly rank with the greatest fears of most of us. During the past few decades, extraordinary progress has been made in many areas of biomedical science research. Once fatal diseases now can be fought with increasing degrees of success. The NIH enjoys the luxury of not having to regularly establish why it does what it does, and why it should be adequately funded by the federal government.

Despite this enviable position, the current fiscal status of NIH is somewhat less than admirable. Although the NIH appropriations rose annually during the 1960's and 1970's, inflation took a great toll in the value of those appropriations jsut as it affected other elements of the economy. The major problem was that for fiscal years 1980, 1981 and 1982, NIH actually lost approximately 5% of its support in real terms. Last year's appropriation reversed that trend and turned the funding level into a real increase for the institutes. However, today, constant dollar funding for NIH remains approximately 12% below the FY'79 level. This means, of course, that despite the substantial funds allocated to NIH -- over $4 billion for FY'83 -- the funds necessary to continue to maintain the level of research activity of recent years are not available.

The Administration is determined to have research operate at levels that are seemly for the great enterprise, but is reluctant to ask for the funding necessary to enable that to occur. It has resorted to a variety of techniques that are designed to give the appearance that things are as they should be. Unfortunately, the public record is quite transparent. Three thousand new and competing grants cannot be made into five thousand similar grants no matter what you do with the numbers. Approximately nine thousand trainees in the National Research Service Award program is 10% less than 10,000 no matter what words are used to describe them. If centers and other mechanisms are funded at lower levels, then that is the case.

In January, the Administration submitted a budget for NIH that called for an increase of $73 million over FY'83 -- an increase of 1.8%. Using the Administration's own figures for inflation, this meant that NIH was being cut in real terms by 2-3%. A revised budget has kept the same funding proposals but moved funds around among the mechanisms to assure a larger number of new and competing grants. Transfers occur from the centers, the Biomedical Research Support Grant program, and training activities. The simple fact is that the budget is inadequate even to meet the Administration's own stated objectives. There are not enough funds to support 5,000 new and competing grants. Instead, an arbitrary number is partially funded, as there are cuts intended in the direct funds for each grant, and there are proposals for trimming indirect costs for each grant. These cuts coupled with transfers that are cuts in other programs, provide the semblance of a continuing program in new and competing grants.

There is a wrenching irony in the essential composition of the Adminsitration's proposed budget. This Administration elsewhere in the federal government has called for increases in funding necessary since it is through the investment in research that many solutions will be found for problems in our economy, foreign exports, creating new jobs, and new knowledge needed for national defense. Given the costs to the economy from absenteeism due to illness, that may be prevented, it is not difficult to relate NIH research as another major contributor to the nation's economy and national defense. The budget, remarkably, facing the need for increased university research, and facilities and equipment that are rapidly aging and becoming obsolete and unusable for research, proposes reductions in programs at NIH specifically designed to fund these areas.

We take special note of the Biomedical Research Support Program (BRSG) as one created to provide the only source of funds available to research scientists to fill unexpected needs, repair essential equipment, provide support for new investigators. BRSG permits university officials to obtain a small piece of instrumentation that prevents research from being delayed, or operating without state of the art equipment necessary. It allows an institution to provide research funds for the young and promising scientist until initial work done with BRSG assistance can win the necessary support directly from the NIH grant competition. The amount of funding in BRSG always has been relatively small; its impact has always been very large indeed.

A special concern to us is HHS's resolute campaign to cut indirect costs reimbursement for all grants. We will not take time here to eloborate on the history of indirect costs and the development of Circular A-21, but instead we attach supporting documents. We only emphasize that the existing regulations for determinng what are appropriate indirect costs reimbursement procedures came about over a very long period of analysis, discussion and negotiation. The universities have been expected to adhere to them. We, in turn, expect the federal government to do likewise. For an agency to decide unilaterally, because it is experiencing a fiscal crunch, that it can dispense with part of A-21 raises far greater issues in a democratic society than the sum of some millions of dollars.

Last year, in the Continuing Resolution, this subcommittee and its counterpart in the House had the Congress call upon HHS to consult with the research community on the proposed cuts of indirect costs reimbursement. We organized our committee last autumn, and repeatedly sought opportunities to meet with officials. For reasons known best to HHS, no meeting took place until Feb. 17, 1983. The invitation to that meeting amounted to an invitation to help choose one of five proposals for cutting indirect costs, rather than discussing fundamental premises where we have major disagreement with HHS. The meeting of Feb. 17 revealed essentially that the representatives of HHS, and NIH in particular, were not prepared to consider the possibility that they were wrong. They had stipulated that cuts were going to occur, and universities were welcome to help design them to be least onerous to them, provided the cuts were maintained.

They now have come forward with a proposal that essentially would determine the average ratio of indirect costs to total costs for the past 10 years, and freeze that as the permanent rate for each institution. There are some other elements in the provision, but they do not change the lack of wisdom and equity in the proposal. For one thing, it is painfully unbusinesslike.

The institutions conduct research, and are expected to be paid for doing so, minus the cost sharing agreed upon by the institution and the federal government. All kinds of events beyond control of the university, such as inflation, affect what the indirect cost rate should be. We have difficulty believing that the federal government would feel compelled to pay a cost rate substantially higher than what it actually was as a result of certain events. We cannot countenance a rate that is irrelevant in the light of events and circumstances after several years.

The major problem with the Administration's proposal is that it is a syllogism that begins with a conclusion and then manufactures premises that necessarily lead to that conclusion. The premises, we believe, are false. If there is a need for further discussion and evaluation of reimbursement for research conducted at universities, then studies need to be done by objective parties, and their findings carefully evaluated for possible changes.

It is true that the current proposals for cutting reimbursement appear to be more thoughtful and rational. Last year, the 10% across-the-board proposal was patently arbitrary, and designed strictly to "save" funds. But the impression that serious thought has been given to this year's proposal is only an impression. The amount of money "saved" still remains approximately $72 million (or 10%), and apparently no thought has been given to implementing such a plan -- a task we believe would be extraordinarily difficult.

We are attaching a document of an ad hoc coalition of some 120 associations and organizations committed to biomedical research. We submit this for the record as a statement with which we wholly concur. The document calls for $414 million for NIH in FY'84 over the request of the President's budget. This would amount to approximately a 12% increase over last year's funding, less than every other major research program. Officials in the Administration have responded straightforwardly to questions regarding the contrast between funding for NIH and other agencies, by arguing that, comparatively, NIH has received sound funding for the past many years, while the physical science agencies have been neglected. As noted earlier in this statement, NIH has not had clear sailing in recent years at all. Nevertheless, it would make no sense at all to reduce every single agency in the federal government to an underfunded state which this policy seems determined to accomplish.

Underfunding NIH at this time belongs to the same logic as postponed maintenance on physical structures. The penalty is enormous. It is very difficult to catch up and to repair the damage. We never truly recapture what we lost, as scientists leave basic research for other enterprises, as bright young minds are not brought in sufficient numbers to the field, as breakthroughs are not made, or when made, cannot be taken advantage of as the entire field of biomedical research, and medicine winds up lagging behind.

Most especially to be considered is the role of the United States as the leading country in biomedical research. In some ways it is akin to the determination two decades ago that we would send astronauts to the moon. Its implications for national image for the entire world are enormous, and the world's awareness of what this country represents as a civilization in producing the finest medicine and medical care possible is very much on the line.

The Chairman is to be commended for his statement to the NIH witnesses some days ago about not buying research on the cheap, and the effects on the out years of shortchanging research in current years. Those comments were directly on the mark, and we applaud them.

Finally, Mr. Chairman we note that the NIH witnesses stated that they were not expecting the states to pick up the slack resulting from federal government cutbacks.

They have every reason not to, given the current fiscal condition of most of our states. But it would appear that unspoken, but necessarily so, is an expectation by NIH that universities somehow will be able to find the funds to make up for cuts in research by NIH. Would that it were possible. Regrettably, it is not. We urge the committee's attention to our proposals, particularly the coalition document that covers the entire range of issues for NIH. We thank you for your continued support for all of biomedical research, and we thank you particularly for the opportunity to appear before you today.

ATTACHMENT I

MORANDUM April 15, 1983

TO: AAU Health and Research Management Committees

FR: Carol Scheman

RE: Indirect Costs/Chronology of Major Efforts to Reverse Cuts

I. On **February 8, 1982**, the Administration sent to Congress the FY '83 budget NIH, with the proposal to cut indirect cost reimbursement by 10%.

II. On **February 22, 1982**, Chancellor Danforth and President Kennedy, on behalf of the AAU/NASULGC/ACE Joint Committee on Health Policy met with Dr. Brandt, Department of Health and Human Services, Assistant Secretary for Health, to protest the proposal to cut indirect costs and to ask if there was any available appeals mechanism within the Department which could result in a revised budget. Drs. Danforth and Kennedy offered their help in organizing a group, representative of the university research community, to meet with the Secretary.

III. On **February 23, 1982**, Dr. Bartlett transmitted a letter from the AAU/NASULGC/ACE Joint Committee on Health Policy to Secretary Schweiker objecting to the indirect cost proposal and urging reconsideration.

IV. On **April 8, 1982**, a group of presidents, vice presidents and deans met with the Secretary and Dr. Brandt. The Secretary cited budget constraints and his concern over the rise in indirect cost as reasons for the proposal. He expressed a lack of understanding of why such costs had increased.

V. On **April 28, 1982**, President Kennedy, on behalf of himself and his colleagues wrote the Secretary to explain why these costs had risen.

VI. On **August 24, 1982**, a delegation of presidents, vice-presidents and deans met with Dr. Wyngaarden, Director of the National Institutes of Health to object to the policy and to seek mechanisms to reach resolution of continued disagreements.

VII. On **September 8, 1982**, the elected heads of AAU, NASULGC and ACE wrote Secretary Schweiker to ask the Department not to pursue the policy of cuts in indirect costs and to offer, if this policy was abandoned, to convene immediately a group to find equitable methods to address the concerns over indirect cost reimbursement. (This letter was overtaken by the following course of events. Nevertheless, there was no reply to this letter.)

VIII. During the month of September and October the House and Senate worked on FY '83 appropriations and assurred staff that the bills would contain both funds and report language to insure full reimbursement of indirect costs.

IX. On **October 25, 1982**, Presidents Kennedy and Shapiro on behalf of the AAU wrote the Secretary "to suggest that appropriate government officials meet with a committee of university representatives to try to resolve the disagreements that continue to plague us over indirect costs."

X. On **October 29, 1982**, AAU staff wrote five AAU members and asked that they and their appropriate university staff and faculty join in this effort (in the assumption that the Dept. would accept this offer).

XI. On **December 15, 1982**, the final FY '83 Continuing Resolution, (including sufficient funds for indirect costs) was filed.

XII. On **December 17, 1982**, Robert Rosenzweig (on behalf of AAU), John Hogness (AAHC), and John Cooper (AAMC) met with Drs. Brandt, Wyngaarden, Maher (ADAMHA), and other Department officials to discuss who should be involved in consultations over indirect costs. (At this meeting Dr. Rosenzweig asked Dr. Brandt if such discussions would be taking place when a budget for FY '84 for NIH went to the Hill with proposed cuts in indirect costs. Dr. Brandt replied that this would not happen if he could help it.)

XIII. Following this meeting, AAU staff called Dr. Brandt's office on numerous occasions to attempt to set up the meeting. (The Department was in a certain amount of disarray immediately prior to and following Secretary Schweiker's resignation.)

XIV. On **January 7, 1983**, Dr. Brandt wrote Dr. Rosenzweig to request a list of suggested representatives for a meeting at the National Institues of Health on January 21. Included in this letter was a draft agenda for these discussions. (It is important to note that although the letter was dated January 7, it was not sent until **January 12** by messenger).

XV. On **January 14** AAU staff replied to Dr. Brandt's request with a suggested list of organizations (including FASEB and ASM).

XVI. Later this same week, the Department cancelled the **January 21** meeting and did not suggest an alternate date.

XVII. On **February 2, 1983**, the Administration submitted its FY '84 budget for the National Institues of Health to Congress including a proposal to cut indirect cost reimbursement by $72M (approximately 10% - essentially the same proposal as in FY '83). This budget was labeled "Draft" and included a letter from then Secretary Schweiker that it would be resubmitted with plans to fund 5000 new grants.

XVIII. On **February 14, 1983**, during a meeting of the Joint Committee on Health Policy, the individuals suggested in the January 14th letter received, by messenger, invitations to a meeting with government officials on February 17th along with a draft agenda which listed alternative methods to cut reimbursement of indirect costs. (The previous Friday, staff had received a call from Dr. Wyngaarden to alert us to this invitation).

XIX. On **February 16th** the AAU, NASUGLC, and ACE responsed to the Departmant's suggested alternatives by stating that such suggestions were an unacceptable agenda.

XX. At the meeting on **February 17th** no conclusions were reached.

XXI. On **March 3, 1983**, the associations submitted to the National Institutes of Health the associations' response to the proposals to cut indirect costs and their suggested process for seeking resolution.

XXII. On **April 8, 1983**, the Administration submitted a revised FY '84 NIH budget that transferred funds from other NIH programs to the grants program in order to fund 5000 grants. The indirect cost proposal remains. The Administration also put the final touches on their plan to cut $72M from indirect costs - that is a fixed allowance based on an individual institution's average of indirect to total costs over the last decade. It is not clear at this time whether or not this proposal has gone to Congress. In this proposal NIH states they have consulted with the research community and intend to consult further before this or any other plan is put into effect.

Senator PROXMIRE. Mr. van der Voort? Mr. van der Voort had a question he'd like to ask.

Dr. ROSENZWEIG. Yes.

Senator PROXMIRE. Go ahead.

Mr. VAN DER VOORT. You were talking about the increase in indirect costs over the past few years, whether in fact, there had been an undue increase. I was wondering how you respond to the notion of an historical basis for indirect costs, so that those institutions that had not experienced undue cost growth would not be hurt badly. Those that had shown a sharp cost growth would, of course, suffer somewhat.

Dr. ROSENZWEIG. I understand that that's the NIH preferred course of action in dealing with this issue. The trouble with it is that you can't pay real costs with historical rates. The question is whether the costs that the negotiated rate represents are real. If they're real, they ought to be paid. If they're not real, they ought not to be paid. That's the basis of A–21. That's what the negotiation over each year's rate consists of. And every university president I've talked to is prepared to talk about indirect costs on that basis, not in terms of some theoretical notion of undue increase or reimbursement on the basis of some average previous rate.

Senator PROXMIRE. Well, maybe that's the way realistically we should operate with respect to this area. By and large with many Government agencies you can understand that when an agency has done what appears to be, at least on the surface, a good job of holding down its costs, we feel that that ought to be handled a little differently than when it is not. But I understand that this is one that doesn't lend itself to that kind of——

Dr. ROSENZWEIG. There's no more depressing issue in all of Government. If I were to list all of the issues involving colleges and universities that I prefer to talk about, this one wouldn't even make the cutoff. It is unfortunate that it's necessary to talk about this issue, but it seems to be a hardy perennial. I urge you to take a look at the report that was issued this week by the Burke Marshall committee of the National Academy of Sciences on University-Government Relations which contains a chapter on indirect costs, which I happened to see yesterday, and it's an excellent statement of the issue.

Senator PROXMIRE. Thank you, Dr. Rosenzweig, very much.

Dr. ROSENZWEIG. Thank you, Mr. Chairman.

Senator PROXMIRE. At this point, additional statements on fiscal year 1984 appropriations for the National institutes of Health, and in particular, the National Institute for General Medical Sciences, will be included.

[The statements follow:]

STATEMENT OF BRUCE S. JACOBSON, ASSOCIATE PROFESSOR OF BIOCHEMISTRY, UNIVERSITY OF MASSACHUSETTS AT AMHERST

I greatly appreciate this opportunity to express my deepest concern regarding the level of funding for the National Institute of General Medical Sciences (NIGMS). I am an established investigator for the American Heart Association spending the vast part of my time conducting basic research and teaching both graduate and undergraduate students. In the brief statement to follow I would hope to convince you that government must not forsake its commitment to basic research and must find ways to increase the number of grants that NIGMS can provide to support fundamental research.

There is ample evidence indicating the valued role that NIGMS plays in the research endeavors of this nation, I am confident that most scientists and physicians doing health related work would agree that the undifferentiated research supported by this Institute has been the underpinning of much of what is discovered by the other institutes that have a categorized mission. That basic research is carried forth and becomes part of our arsenal to combat human maladies has been documented in previous statements to your committee and in many scientific journals as well as newspapers and magazines. Most often these journals focus on the more spectacular, single events. Unfortunately, what they at times fail to point out and what the public sometimes does not recognize is the years of work performed on basic research models by dedicated men and women in many laboratories throughout this country. Fortunately, many of our legislators are aware of this and have been convinced that the work supported by NIGMS is of the utmost importance. However, what is of great concern is just how much of this type of research should be supported, especially in light of our current economic difficulties.

It is difficult but not impossible to weigh or predict the value of what the current research supported by NIGMS is going to contribute in the future. While we could answer this by pointing out the tremendous strides made in better understanding of diseases and their control, we should not forget the burgeoning industry of biotechnology. I would trust that this field which has its roots in discoveries made by various investigators who were no doubt supported by NIGMS will continue to grow and provide humanity with as yet undreamed of products. Rather than discuss these more global consequences of basic, undifferentiated research, I would like to relate to you an example of how one small project at the basic level provided necessary information to conduct work with humans.

I would like to draw upon some work I did as a graduate student to give a specific example of how discoveries move from the lab bench to use in human disease. I am confident that my more recent work will also find its way to helping other scientists and of course our citizens, but it is too soon to tell just when and in what way it might occur. While a graduate student being supported by NIH predoctoral fellowships, I was working on the metabolism of potato tubers. We knew that wounding a potato, like wounding mammalian tissue, caused a burst in respiration. We wanted to know what the potato was using as its source of energy. We could not feed the potato external food sources since it had all of its possible energy reserves within itself. Fortunately, previous work on photosynthesis "the making of energy from light" had indicated that carbohydrates were synthesized with a different ratio of a variant of the carbon atom called an isotope than were the fats. I should point out that these variants are not radioactive isotopes but are stable ones and are normally present in our own bodies. One stable isotope, carbon-12 is most abundant, being about 99% of the total while carbon-13 is the balance. The fats have even less carbon-13. Therefore, by measuring the relative amounts of carbon-13 in the respired carbon dioxide we determined that the potato used its fats for producing respiratory energy. It took several years to establish this. How is this relevant? It turns out that in man and other animals, an indication of diabetes is a preferential use of fats and as you can expect we showed that the same methods used with potatoes could diagnose chemically induced diabetes in rats as well. Based upon this work another group used the same approach to conduct similar studies with humans. The references to this work are given at the end of my attached curriculum vitae. Many people do not realize that there is a tremendous underlying similarity to life processes throughout the biological world and would be surprised to find that research on potatoes would have any relevance to human disease. This very concept of similarity of life processes is of vital importance to modern health research and is itself a product of accumulated untargeted research. The example of the relationship of studies in potatoes to studies in humans also gave me a personal reward and that is a sense of accomplishment and a strong desire to be involved with discovery at the basic level and to watch it progress to the applied. I am sure similar feelings are in the minds of other investigators. It is one reason why I can say without reservation that basic research scientists are very dedicated, hard working people and as such society gets maximum productivity for its tax dollars.

I hope this minor example and others I am sure you have will convince you that the research supported by NIGMS is probably the most valuable of any institute for providing the tools for future health related research. Without NIGMS, work in other institutes as well as industry would rapidly begin to lose momentum. I trust we would agree that NIGMS grants provide a most essential foundation and if we do not continue to fund this institute to the highest level, other research institutes will soon waiver or will have to divert their resources to undifferentiated research--an approach better carried out by those with the years of experience and expertise, i.e., NIGMS grant awardees.

As a closing note, I would like to emphasize that reducing the budget requested by NIGMS would not only tear away at our future scientific needs but it would create a see-saw funding attitude which is a very inefficient way to conduct research. You just do not turn basic research on and off again. It is a continuum in each and every laboratory and interrupting that flow to wait for better economic times means, in most cases, a more than inordinate set back if not a complete loss, in particular of those people with highly trained skills and keen minds. The loss is not just to the investigators but to us all.

Statement of John B. Schenkman, Ph. D., Professor and Head, Department of Pharmacology, University OF Connecticut Health Center

Thank you for the opportunity to testify on behalf of the National Institute of General Medical Sciences and to express for the record my opinions as to its budgetary needs. Permit me to introduce myself. I am Professor and Head of the Department of Pharmacology of the University of Connecticut Health Center, a position I have held since 1978. For ten years prior to coming here I was a faculty member in the Department of Pharmacology of Yale University School of Medicine. I am a member of several scientific societies in this country as well as one each in Great Britain and Germany. I have served as a member of the Pharmacology Study Section, a peer review committee for Grants Review, for four years and have served on numerous Site Visits of research grant applicants. I am currently a member of the NIGMS Pharmacological Sciences Review Committee, a peer review committee for Center Grants, Program Projects and Training Grants. I am the author of one book and about 90 original scientific publications in reviewed scientific journals. I am on the editorial board of three of this country's leading scientific journals and one international review journal.

Since earning my Ph.D. degree, almost every stage of my scientific development has been nurtured by support from NIGMS. My postdoctoral research was supported by a GMS grant and my postdoctoral advisor was a GMS Research Career Development Awardee. I set up my own laboratory at Yale University with research support from GMS. Later, a Research Career Development Award from GMS provided me with sufficient independence and time to develop my research skills and become an expert in my area of research. I have held continuous research grant support from NIGMS since 1968. A more complete bibliography is provided at the end of my testimony.

Dr. Ruth Kirschstein has testified before you, I believe, on the specific programs supported by NIGMS, the Investigator-initiated grants, the Research Centers supported, the Program Projects, Training Grants and In-house Research, and the specific funds needed to support each. In my estimation, strong support is warranted for all of the programs of NIGMS, especially now, after a long period of neglect. Strong support would be taken by both current and future scientists as a statement of commitment to biomedical research, and more than anything else encourage our nations brightest students to embark on careers as research scientists. For my part, I wish to address in my testimony my perception of the needs for strong financial support of the programs of NIGMS.

Scientific research is cost-effective. Although the costs of scientific research are rising rapidly, technology and the pool of knowledge are growing even more rapidly. As a result, the productivity purchased by a dollar today has increased dramatically. For example, a few years ago the man-years of work and associated costs of maintaining a primary cell culture for research studies would have kept most laboratories from attempting to conduct research on isolated cells in culture. Today, modern technology and published procedures make studies with such cultures inexpensive and relatively easy, affordable and commonplace. While inflation has doubled prices and costs since 1974, the growth of knowledge and technology has more than met the challenge, making scientific research a bargain by any standard. To this we can add the indirect, but by no means small, economic fall-out from biomedical research--the non-disease related benefits. The American businessman has been and probably always will be an opportunist. Wherever a need is perceived and knowledge gained from basic research will fill that need a market develops. The businessmen in this country have rapidly pounced upon any and all usable basic information such as that supported by GMS and have created whole new industries. Results have been seen in genetic engineering as well as the multibillion dollar biomedical support industry, designed to supply anything from interferon and insulin to antibodies and chemicals to electron microscopes. In jobs and developing technology alone medical research has been a boon to the public, and the scientific knowledge has provided a basis, certainly an indispensable part, of knowledge adding to the quality as well as to the duration of life.

I view NIGMS as fitting in the center of the picture. Alone of the Sister Institutes it does not have a disease oriented mission. Its role has been to seek out knowledge of the processes of life, upon which disease-oriented studies may build. No discovery, however revolutionary or insightful, can be made in the absence of an underlying strata of facts and understanding. This strata of knowledge grows with each fact of information gained, even as the parts of a picture puzzle begin to become recognizable with each piece added, until finally a "discovery" is made.

Because of the basic nature of the work supported by NIGMS it is most vulnerable to attack, with critics often unable to see where supported studies fit into the picture of human health. Pressures for mandated set-asides for small business, for AIDS, for Orphan Diseases and the more rapid growth of indirect costs of research all erode the level of support available for investigator-oriented basic research. We must be vigilant lest support for these other worthy causes be at the expense of the essential basic research studies; the basic research provides the underlying basis for the more directed or disease oriented research. If support for NIGMS is deemed justifiable, then it must be at a sufficiently increased level to allow a steady increase in the rate of gain of new knowledge in order to keep up the momentum of the past decade.

The waning of research support over the last few years has caused considerable problems for basic research. In an attempt to provide a broad base of supported Investigator-originated research grants in the face of waning government commitment, Institute-mandated cuts in the research budgets of funded grants of 4% to 10% of the recommended amount have been implemented. Some investigators have called for deeper cuts, to keep open more laboratories and prevent irretrievable loss of research groups. What is not considered is the deleterious effect such cuts cause on the performance of the proposed research projects in the grants. When a peer review Study Section gets through with a grant budget, there is no fat left. Any cut means a loss in flexibility for the researcher to track down the knowledge being sought and could be extremely deleterious to the final fruition of a study. Further, such cuts might carry the erroneous signal to Congress that fat does exist in the funded grants. Thus, a dilemma exists; neither of the solutions being suggested will suffice. Science, like coals in a furnace, which burn more strongly when surrounded by other hot coals, needs a constant supply of hot new data to keep synthesizing ideas and generating new hypotheses to test. The concept of "critical mass" also applies to basic research. We must prevent the rate of influx of new ideas from falling to a point where it impairs or becomes limiting to the development of new understanding of the biological processes. The only viable solution is a sizable increase in the budget for NIGMS to permit a broad base of supported research grants without impairing the budgets of the funded grants.

The last point I wish to address concerns support of research training. NIGMS has played a major role in supplying current and future needs of this country for biomedical research scientists. For the past two years I have had the opportunity of interviewing young research trainees in several of our institutions of higher education. The Ph.D. trainees I have spoken with were uniformly of exceptionally high caliber and enthusiastic, highly motivated persons. NIGMS is to be commended for the foresight and persistence with which it has protected and provided for this vital need with its support. Without a continued support of high quality trainees, as carried out under the NIGMS multidisciplinary programs, we would not be assured of enough highly talented, versatile new researchers to meet the future needs of this country. NIGMS has, more than any of the other Institutes, made this effort. One area in need of augmented support is postdoctoral training, to similarly provide for advanced training of our more outstanding Ph.D. graduates.

Research training is a long and arduous task, involving a close interaction between a mentor and a student, followed by the weaning of the neophyte scientist to bring forth an independent researcher. It requires the student to dedicate four or five years of his or her life to hard work and study to earn a Ph.D. degree. If the student chooses a subsequent career in academic research, it will require anywhere from an additional two to four years of training in postdoctoral research. It is only after this period that the student has earned the confidence of his or her seniors to receive an independent laboratory and to apply for independent research grant support.

By then, following the usual route from high school to college, the student will have taken his or her first job at age 31. This is a very long gestation period and only the more strongly motivated take it. From the major impact such individuals have on our nations health as well as upon its economy, strong support of these programs is warranted.

In summary, NIGMS has long supported the basic studies of science upon which other, more disease oriented research, feed. One needs only glance at the grant citations in any quality journal to note that quality has been the Hallmark of this Institute. Its successes are not read as diseases cured, but, as those with insight recognize, in the underlying contributions which make such cures possible. Without the contribution of NIGMS supported studies there would be few successes in attempts to enhance the quality of life and its duration in this country. In my estimation, NIGMS warrants the highest level of support possible.

Thank you, again, for this opportunity to testify on behalf of the National Institute of General Medical Sciences.

STATEMENT OF BEVERLY B. BYRON, U.S. REPRESENTATIVE FROM MARYLAND.

Mr. Chairman, it is with great pleasure I make these introductory remarks in behalf of a respected constituent and a highly regarded surgeon, Dr. John W. Clark, of Hagerstown, Maryland. Dr. Clark's father, as you will note in the addendum, was the founding Medical Director of the Gorgas Memorial Laboratory and Institute. Dr. Clark can clearly remember many incidents, with fondness, concerning the development of the Laboratory into a major, international institution specializing in tropical and preventive medicine. Dr. Clark was recently elected to the Board of Directors of the Gorgas Memorial Institute.

We can all remember from our junior and senior high school history classes, the exciting details concerning the construction of the Panama Canal as well as the problems which evolved during that tremendous undertaking. In fact, the Gorgas Institute had its origin, in 1928, in a joint, United States-Panama initiative, to commemorate the great work of William Crawford Gorgas in the control of malaria and yellow fever while the Panama Canal was under construction.

The record shows that the Laboratory progressed as a leading science research center specializing in tropical and preventive medicine. With the enactment of PL 70-350, the Laboratory obtained a permanent authorization to the core funding component for the maintenance and operation of the Laboratory within the Institute. This line item was subsequently transferred from the State Department to the Fogarty International Center.

Mr. Chairman, as a member of the Armed Services Committee, I am well aware of the training and support activities of the Laboratory and Institute which are utilized by the Department of Defense. The Gorgas Memorial Laboratory has, among other accomplishments, a long and illustrious military history of scientific excellence. From a DOD point of view, it was the first laboratory of scientific repute in Central America and has made numerous contributions to tropical medicine, many of which are the basis of the preventive and control strategies utilized by our troops today.

The Gorgas Laboratory enjoys a unique position in relationship to the countries of the Americas and, alone among the facilities available to the U. S. Government, has entry into virtually any country. Listed below are areas the Laboratory has worked in, which have been of help to the U. S. Army:

1. Development of primate models for malaria.
2. Testing of new anti-malarial drugs.
3. Early field trials of DDT during the Second World War.

4. Worked out the biology and epidemiology of the viral encephalidities of Central America.

5. Worked out the biology and epidemiology of sandfly fever and related viruses.

6. Monitoring the progression of jungle yellow fever through the Americas.

7. Worked out the biology and ecology of the mosquitoes which are the fectors for malaria, yellow fever, Venezuelan equine encephalitis, dengue, and St. Louis encephalitis which forms the basis of our present control methodologies.

8. Worked out the pathology, clinical picture and treatment of new world cutaneous leishmaniasis.

9. Assisted the Army in the sea level canal studies. Prepared the section on medical ecology.

Three U. S. Navy personnel are on duty at the Laboratory at all times under a permanent assignment agreement with the Institute: a medical officer, researcher, and a chief hospital corpsman. In addition, the Laboratory conducts, for U. S. Navy medical officers, a six week training program on "Medicine in the Tropics", four times a year. Seven medical officers are enrolled in each course.

The U. S. Navy/Laboratory staff continues to make many educational improvements to enhance the comprehensive program. Arbovirologic diseases, preventive medicine, general epidemiology, serodiagnosis, and heat related illness studies have been expanded. Also of high importance, more clinical data and facts have been made available by adding hospitals in nearby provinces for clinical rounds.

Aside from the Navy physicians, students come from a variety of medical centers such as the Uniformed Services University of the Health Sciences, the U. S. Air Force, Gorgas Army Hospital, Johns Hopkins University, University of Pennsylvania, University of North Dakota, and the German Navy Medical Corps. Likewise, throughout the years, many of the Laboratory staff have lectured at local and distant medical and scientific conferences.

Therefore, it was with keen interest that I read the printed hearings of the House Subcommittee which included last year's discussion of the Gorgas Memorial Institute. I noted that, subsequent to the hearings, a language change was adopted in markup. In this regard, I particularly call attention to the question Congressman Joseph Early put to Dr. Claude J. M. Lenfant, Director, NIH, as follows: "You are requesting appropriation language to place a ceiling on the amount available for payment to the Gorgas Memorial Institute for maintenance and operation of its laboratory. Why are you requesting this ceiling?"

Mr. Chairman, Dr. Lenfant's answer clearly states: "The language proposed maintains the Gorgas Memorial Institute (GMI) as a line item in the Fogarty International Center (FIC) budget, but it restores language from previous appropriations which specified that the designated amount for the Gorgas Memorial Laboratory (GML) could not be exceeded."

Dr. Lenfant added later in his answer: "The funds for the GMI are an integral part of the budget of the FIC and of the NIH."

Dr. Lenfant continued to explain the ceiling as a "balanced approach" and, to me, he infers that any overage above the core line item of $1.8 million will be judiciously allocated for other budget activities. Now we see there is nothing in the NIH budget request for either the Laboratory or the Institute. This smacks, not of a budget cut, but more of premeditated, professional chicanery, prompted by economic rivalry within the NIH.

The implications for the Gorgas Institute are extremely critical. Dr. John Clark advises me that if the maintenance and operation funds for the Laboratory are not available on an annual basis (which the Institute has utilized for 55 years), then the Laboratory will have to shut down. In other words, Mr. Chairman, unless your Subcommittee decides otherwise, last year's language change may have legislated the end to the Laboratory and the Gorgas Memorial Institute.

Mr. Chairman, since I am not a member of your distinguished Subcommittee, I do not pretend to have all the answers, but do respectfully request that you and your colleagues view this matter with a critical eye. I commend to the Subcommittee, the statement of my very competent and qualified constituent, Dr. John W. Clark of Hagerstown, Maryland. It just seems incongruous that an Institute that has been an integral part of our defense effort and our tropical disease research for so long, with the potential to become an essential element to President Reagan's Caribbean Basin Initiative, would be terminated in such an abrupt and surreptitious manner.

I am now pleased to include the statement of Dr. Clark.

STATEMENT OF JOHN W. CLARK, M.D., GORGAS MEMORIAL INSTITUTE

Thank you Congresswoman Byron for your introductory remarks and my gratitude to you Chairman Weicker for the opportunity to submit this statement for the Record. This is an overview of the Gorgas Memorial Institute And Laboratory of Tropical And Preventive Medicine.

The Gorgas Memorial Institute is a non-profit corporation, chartered under the laws of Delaware, and registered in Panama, with corporate offices in Washington, D.C. The Gorgas Memorial Laboratory, the operating arm of the Institute, is located in the Republic of Panama. The primary purpose of the Laboratory is to conduct research into the basic, applied and clinical sciences of tropical medicine.

The Laboratory was established in 1928 as a living memorial to William Crawford Gorgas, whose genius in preventive medicine led to the control of yellow fever and malaria and permitted construction of the Panama Canal. The French had failed because of these diseases. American engineering ingenuity and the control disease succeeded in the development of the most impressive waterway in the world.

HISTORY

Under the initiative of the then President of Panama, the Institute was organized in 1921. The ground and building for the Laboratory were contributed by Panama in 1928.

Since that time, it has grown and expanded. It is internationally known for both the quality and the volume of its work and has gained a reputation for excellence as will be outlined in the following discussion.

THE CURRENT PLAN

There are four buildings within a large city block, named according to function: Administration Building, Research Building, Animal House and Insectory.

Of the 100 employees, 18 are established scientists.

FUNCTIONAL HISTORY

Since its inception, research has been conducted into many areas: parasites and parasitic diseases of man and lower animals, viral and rickettsial diseases, bacterial diseases, medical entomology and other areas. More specifically, these include: malaria, American trypanosomiasis, leishmaniasis, intestinal amoebae and worms, yellow fever, dengue fever, tuberculosis, diarrheal disease, brucellosis, climatology and geographic pathology, to list only some of these efforts.

About 1,000 articles have been published in medical and scientific journals.

PIONEERING FIRSTS

There are well over 50 outstanding "pioneer" accomplishments recognized throughout the scientific community:

- First transfer of human malaria to monkeys and back to humans
- First discovery of certain wild animals as reservoir hosts of human leishmaniasis.
- First isolation of a number of new human viral diseases of the tropics.
- First isolation of several major viral diseases in Panama, e.g., Q fever, St. Louis encephalitis.
- Discovery of mosquito vectors of yellow fever in Central America which maintains a reservoir for periodic epidemics.
- Discovery of disease transmitted by vampire bats...a fractional listing.
- Discovery of an endemic rodent-mosquito-rodent cycle of Eastern equine encephalomyelitis which serves as a reservoir for epidemics in horses andman.

"Firsts" are spectacular, but the mention of these is not to depreciate the steady accretion of scientific knowledge that is represented in all the other papers mentioned above. As one explained of science stated, "We build like coral polyps."

RELATIONSHIPS: OTHER INSTITUTIONS

The Laboratory has served as host to visiting scientists from and/or otherwise collaborated with many outstanding organizations, including the following universities, Johns Hopkins, Rochester, California, Cornell, Yale, Madras (India), Harvard, Baylor, Virginia, Michigan, Caracas (Venezuela), Tulane, Chicago: also the Smithsonian, Rockefeller and the London School of Tropical Medicine ...again, a partial listing.

RELATIONSHIPS WITH CARIBBEAN REGIONS

The relationships between the Laboratory and the Republic of Panama have been most supportive and active since the very beginning of the Laboratory when the original property was deeded to the organization. The future of the Laboratory in the Republic appears to be secure in its relations with the Republic.

Indeed, the response of the Republic of Panama to the needs of the Gorgas Memorial Laboratory is tantamount, proportionately, to a contribution in dollars much exceeding that provided by the United States.

NEED FOR THE GORGAS LABORATORY

The need is a reflection of past accomplishments plus future needs of the United States. Spin-off occurs to Panama and to the International medical/scientific communities.

- Many human and animal diseases previously classified as "tropical" and studied by the Gorgas Laboratory are now becoming public health problems in the United States, particularly in New York City, Baltimore, Florida and Texas. Equine encephalitis is one of those diseases. Much additional investigation is needed as more problems become evident.
- The Gorgas Laboratory is an established, reputable training center for upcoming biomedical scientists. In addition to American graduate students who have "matriculated" through the Laboratory, it has served as a training center for the medical departments of the U.S. Armed Services since 1931.
- It has served, and continues to serve, as a sentinal for warnings about the incursions of yellow fever, equine encephalitis and other tropical diseases, into new territory in Central American, thereby threatening the United States.
- As is obvious from the current news, Central America and the Caribbean area continue to be a region of foment, presenting many problems in our relations with them. Here is a positive area of support with many mutual benefits to both the United States and to the Caribbean arae. It represents a stabilizing influence between the governments of the United States and the Republic of Panama.

This completes my statement Mr. Chairman. As an addendum, for the Record, I submit the following article from the Oct. 4, 1952 Saturday Evening Post, concerning my father's work at the Gorgas Memorial Laboratory.

(Clerk's note.—This material is contained in the subcommittee's files.)

STATEMENT OF RODY P. COX, M.D., PROFESSOR AND VICE CHAIRMAN, DEPARTMENT OF MEDICINE, CASE WESTERN RESERVE UNIVERSITY, CHIEF, MEDICAL SERVICE, CLEVELAND V.A. MEDICAL CENTER

I enthusiastically support an adequate budget for the National Institutes of Health and for the Institute of General Medical Sciences (NIGMS) in particular. Development of new and effective treatment for diseases depends upon an understanding of fundamental life processes. The research supported by NIGMS is primarily devoted to basic studies on structure and function of cells. An understanding of regulation of cell metabolism and expression of genetic information by cells is one of the most challenging areas for investigation. The pioneering research on molecular genetics, primarily funded by NIGMS, is providing the methods necessary for understanding cell controls and gene expression. These basic studies are already being applied to clinical medicine through improved methods for diagnosing genetic diseases in utero, examples of which are sickle cell anemia and Mediterranean anemia. Moreover, studies using molecular genetics have revealed several "oncogenes" that probably play an important role in the development of cancer. It is clear that the research supported by NIGMS is seminal in developing innovative and new approaches to disease. The application and refinement of new knowledge to specific diseases is often carried by the categorial Institutes at NIH.

A matter of grave concern to me and to many medical investigators is the training of physicians in research. It is important that both M.D's and Ph.D.'s carry out research since they tend to ask different questions that provide complementary information. In recent years there has been a substantial decline in the number of physicians entering biomedical research. In part, this shift in physician career choices is due to the complexity of theory and technology required to carry out sophisticated and competitive biomedical research. Also, as the current cadre of clinical investigators age, there will be an increaseingly acute shortage of physician-scientists. The Medical Scientist Training Program (MSTP) supported by NIGMS is a major initiative in remedying the shortage of physician-scientists. The combined M.D.-Ph.D. Program is the most efficient and probably the most effective program for developing physician-scientists. The MST program enables highly motivated students to acquire the theoretical and quantitative methods of a basic science (Ph.D.) that prepares them for a career in research while they also learn the clinical skills necessary for medicine (M.D.). Scientific training begins soon after completing college while the principles of basic science are current. Trainees undertake research in a basic biomedical science under the day-to-day supervision of a research mentor. They carry out original investigation and acquire knowledge in parallel areas that help them devise new methods for approaching their areas of research. The completion of the Ph.D. degree is probably the most effective preparation for a career in research. The flexibility of MST programs enables trainees to tailor the curriculum to individual needs. During their laboratory training, students also are exposed to the unique challenges and opportunities of clinical investigation. This combined and integrated training format prepares talented young scientists to assume leadership roles in biomedical investigation. The MST graduates (M.D.-Ph.D.) will ensure the continued health of biomedical science in the United States and provide new effective methods for preventing and treating human diseases.

I urge that these programs at NIGMS receive a high priority for funding. I appreciate the opportunity to present my views that are shared by most academic physicians.

STATEMENT OF DR. ROBERT GREEN, DEAN, UNIVERSITY OF CONNECTICUT SCHOOL OF SOCIAL WORK EDUCATION, APPEARING ON BEHALF OF THE COUNCIL ON SOCIAL WORK EDUCATION

Senator PROXMIRE. Now we go into the Alcohol, Mental Health, and Drug Abuse Administration. Our first witness in this area is Dr. Robert Green, who is the dean of the University of Connecticut School of Social Work and appearing on behalf of the Council on Social Work Education.

Dr. Green, happy to have you here.

Dr. GREEN. Thank you very much, Senator. I'm active in the Council on Social Work Education, which is an organization composed of 83 graduate schools of social work and over 200 undergraduate programs in leading colleges and universities across the country. Over 40,000 students are enrolled in these programs. Our concern is with the education of individuals to serve in administrative, research, and service delivery roles in the mental health and social welfare system.

We're testifying today on training in mental health administered by NIH, child welfare as administered by the Children's Bureau, OHDS, and on the research program of NIMH.

At the outset, Mr. Chairman, permit me to express our appreciation to this committee—and being from Connecticut, especially to the Chair—for a constant commitment to the provision of quality social service to our people in need and to the training of qualified personnel to administer and provide those services.

Let me briefly describe three of our federally-funded programs at the University of Connecticut.

First, our Puerto Rican studies program has allowed us to begin to help meet the increasing needs of the large Hispanic population in New England. We have been able to hire Puerto Rican faculty, recruit and educate Puerto Rican students, develop special curriculum and practical experiences, and because of strong and repeated support from the media, State, and agency personnel and citizens served, we have been receiving additional funds from both the university and the State of Connecticut.

Our child welfare technical assistance program is run with undergraduate and graduate social work programs. In each of the New England States, we have developed joint cooperative efforts with the private sector, while focusing our major joint effort on and with the New England public agencies concerned with the welfare of children.

We have helped State agencies begin to realize their goals for training administrators and staff, so as to meet the highly acclaimed congressional goal of assuring all children the rights, protection, and service every humane society would guarantee them.

Finally, our rural social work grants focus on what we southerners refer to as Northern New England.

We are, with this committee's support making a difference, especially in Maine and New Hampshire, by upgrading services through working with public and private agencies. We're helping more than 200 social service workers gain new skills and knowledge by offering on-site graduate education courses in five to eight communities in the northern tier. Since the grant does not nearly cover all costs, individual students, the tuition payment, together with the university, contribute significantly to finance the program. Thus citizens, the Federal Government and the State university cooperatively strive to make our region a better place to live in.

These are the programs that are in jeopardy, Mr. Chairman. They work. They are cost effective by any measure, and they contribute to the general welfare.

The material already submitted for the record argues in detail for the points I will now attempt to summarize. In creating an essentially new mental health training program by the 1983 appropriation, Congress sought to insure equity support for the four core disciplines. The records indicate, however, a great disparity with social work training proposed support and only 19 percent of the $14.5 million allocated. The priorities established to insure the training of minority students, child mental health and geriatric mental health workers, and those who provide services in rural areas, we believe, should be extended to include those working in community services for the chronically mental ill and for minority populations.

Disciplines should be awarded funds, Mr. Chairman, upon the ability to respond to the service priorities set by Congress. We wish to stress again the need for the training of minority students and of requiring service payback by all beneficiaries of training grants.

We believe clinical training programs should grow substantially in fiscal year 1984. So few approved grants were funded for fiscal year 1983, that the appropriate level should be increased to $30 million. NIMH research funds must be utilized to develop adequate manpower supply and need projections and models which can be continually updated.

The Child Welfare and Adoption Assistance Act of 1980 requires that trained professionals deal effectively with the problems of child placement, adoption, and child abuse.

Recent studies, which I give in more detail in the material submitted for the record, of programs in 25 States demonstrate the inadequacies of current staffing and the effectiveness of well-trained professionals. $5.6 million was appropriated for fiscal year 1982 and recommended by this committee for fiscal year 1982 for child welfare training, provided through OHDS. Currently, however, one-third fewer trainees and teaching grants are being supported. While the administration would fold the entire program into a block grant, we urge support at the fiscal year 1982 level to support 600 trainees and some 60 teaching grants.

We are opposed to HHS plans to allow many programs to compete with social work for this one traditional source of social work child welfare training support.

We also support the continuation of the recently established 10 regional child welfare training centers across the country. These centers are targeted for elimination by OHDS, but Mr. Chairman, they provide needed and valued support for public child welfare agencies across this Nation.

Finally, we urge NIMH to fully recognize the valuable contribution social work educators and practitioners can make, as it awards research grants during the coming year. Major research efforts should focus on conducting comparative research on the major methods of providing service, especially in community settings and on treatment provided by the various disciplines.

Mr. Chairman, we thank you for the opportunity to testify. We'd be glad to try to answer any questions.

Senator PROXMIRE. Thank you very much, Mr. Green, we very much appreciate your statement.

[The statement follows:]

STATEMENT OF DR. ROBERT GREEN

Mr. Chairman and members of the Subcommittee, I am Dr. Robert Green, Dean of the University of Connecticut School of Social Work, and I am active in the Council on Social Work Education (CSWE) Governmental Affairs Committee. CSWE is an organization composed of 83 graduate schools of social work and over 200 undergrduate programs for social work in leading colleges and universities across the country. Over 40,000 students are enrolled in these programs. In addition to educational institutions, there are 4,800 members of CSWE, including voluntary and public national, state and local social welfare agencies and related organizations, faculty members, and individuals concerned with social work education. Our concern is with the education of individuals to serve in administrative, research and service delivery roles in the mental health and social service systems. We are testifying today on training programs in mental health, administered by NIMH, child welfare, administered by the Childrens' Bureau, OHDS, and on the research program of NIMH.

At the outset Mr. Chairman, permit me to express our appreciation to this Committee for its consistent commitment to the provision of quality social services to our people in need -- and to the training of qualified personnel to administer and provide those services.

1. The Federal Role in Support of Professional Education

The current economic problems of the country, including severe unemployment in many areas create a greater demand for mental health and social service programs. The Congress and President recently recognized this in adding service funding to the Supplemental Appropriation bill earlier this year. As more families fall into low income, poverty and "no income" situations, there are greater demands placed on our social programs as well as our income support systems. We must support those social programs particularly in these times. Without that support the costs to society will be far greater than the costs of those programs; economic costs such as related to permanent income support and the more human costs related to distress, family break up, etc.

We believe that mental health service programs, child welfare service programs, and social service programs generally are of great importance, particularly at this time, and that the Federal role in those programs must be maintained. We think that those programs should all be funded to allow for real growth. We defer to those organizations such as the National Mental Health Association and the Child Welfare League on the specifics of these programs.

The importance of professional education for those providing and administering social programs grows as the need for these programs grows. Mental health and child welfare programs, as well as other health and social service programs are only as effective as the individuals managing and providing the services. Appropriate, quality educational programs for social workers to prepare them for their roles in staffing mental health centers and similar mental health programs and public and private child welfare agencies is crucial in order to have effective service programs in these areas. Continued Federal support is necessary in professional education programs in mental health and child welfare for two reasons: to assure an adequate supply of well trained professionals for the service programs involved, and to assist in providing equal access to education and the helping professions through traineeship assistance to needy students, particularly minority students. Both the mental health training program of NIMH and the child welfare training program of the Childrens' Bureau in OHDS serve those purposes. Both programs target training support on students and personnel who will be or are in the agencies and service systems most in need of professionals. The recent "National Follow Up Study of the Child Welfare Training and Trainees", 1981, supported by the Childrens' Bureau, shows that 61% of students trained were employed in child welfare agencies, both public and private. These two training programs have afforded social work education the opportunity to attract highly qualified young people for careers in social work including minorities and the disadvantaged. These talented people then practice their skills in programs which need professionals most.

2. Mental Health Training

In the FY 1983 appropriation legislation, Congress and this Committee essentially created a new mental health training program. That program is focused on providing support to train professionals in identified areas of shortage such as serving minority populations and rural populations, children and the aged. The Congress stressed the need for equity in support for the four core disciplines of psychiatry, social work, nursing and psychology. We were initially disturbed by the NIMH special focus on only two disciplines: psychiatry and nursing. NIMH revised its approach somewhat but the figures reflected in the 1983 column of the FY 1984 clinical training budget still show serious inequity between disciplines.

The following analysis is based on material reflected in the President's FY 1984 budget submitted in February. The general reduction between the FY 1982 and FY 1983 mental health training budget for the four core disciplines was a bit more than 50%. The distribution among the four core disciplines varied enormously, however, reflecting very little equity. Social work support has been reduced by about 63% whereas psychology is reduced by a bit less than 50%; nursing by only about 30%; and psychiatry by about 58%. In terms of each discipline's share of the total program, obviously social work's dropped markedly, psychology's stayed the same, and psychiatry's dropped a bit. Of the total $14.5 million allocated to the four core disciplines in FY 1984, there is still a significant imbalance. Psychiatry programs constitute about 37% of the program, nursing about 24%, and psychology and social work about 19%. Looked at either way, serious questions of equity remain.

For FY 1984, we strongly support the Congressional redirection of the clinical training program begun in FY 1983. The program should focus on specified national priorities which are based on determinations of shortages of qualified professionals. We believe that, as in FY 1983, these areas should include training of minority students, child mental health, geriatric mental health and services to those in rural areas. We would recommend that, in addition, priorities be established which relate to community services to the chronically mentally ill and services to minority populations. We do not believe that any special priority or treatment should be provided to any particular disciplines, per se, but that the disciplines should respond to the shortage areas designated as priority. There should, however, be an equitable proportion of grants funded among the four disciplines. The evidence of personnel shortage exists for all four disciplines with respect to the priority areas. Each should receive an equitable proportion of the grants awarded in each priority area.

We wish to particularly stress the importance of the priority of training minority students and of requiring the service payback for all beneficaries of training funds. We do not believe that enough funds were spent on the training of minority students relative to other priority areas. We believe that area should be funded with the greatest amount of training funds.

We believe that the new clinical training program should grow substantially in FY 1984. Applications for grants reached historic heights but the grants awarded in FY 1983 were few and had highly meritorious scores. Generally, they should be continued in FY 1984. In addition, since so few approved grants were funded in FY 1983, and since the priorities established which we have recommended continue, we would urge an appropriation of at least $25 million and preferably $30 million. We think some NIMH research funds must be used in FY 1983 or FY 1984 to develop adequate manpower supply and need projections and models which can be continually updated. We think such a budget is clearly justifiable.

Major analyses of mental health (including findings by the President's Commission on Mental Health), indicate the need for a greater number of professionals serving in community programs for minorities, the aged, children and the chronically mentally ill. See "ADAMHA Manpower Policy Analysis", 1978, Vol. I, pp. viii to xi.

3. Child Welfare Training

Training of professionals to serve in the child welfare area is equally as critical as in the field of mental health. As with mental health, national standards regarding the quality of services and the focus of services is needed. The Child Welfare and Adoption Assistance Act of 1980 reflects a national commitment to deal with the problem of inappropriate placements of children, failure to monitor the cases of children removed from their natural homes, and inadequate programs to encourage adoption. This needed national program should be fully funded at authorized levels. The program requires trained professionals to deal effectively with the problems of child placements, adoption and child abuse. Recent studies of child welfare agency programs in 25 states, "Child Welfare Programs - a 25 State Study", by the Child Welfare League and Peet Marwick & Mitchell, and of child welfare in Alameida County, "Children in Foster Homes: Achieving Continuity in Care", 1978, have demonstrated the inadequacies of current staffing and the effectiveness of well trained professional staffing of child welfare agencies.

The $3.8 million of child welfare training support provided by the OHDS, through the Childrens' Bureau, is essential to provide continuing education and training to child welfare agency personnel, and traineeships to needy students of whom about 1/3 are minorities. A substantial majority of these trainees (61%) end up practicing in publicly-supported child welfare agencies. The budget for child welfare training has been cut by 50% since FY 1980 when it was $7.5 million. With $5.6 million as appropriated in FY 1981 and recommended by your Committee for FY 1982, 610 trainees, 11 regional child welfare centers and some 60 teaching grants were funded. In FY 1982 and FY 1983, funds cover about 1/3 fewer trainees and teaching grants. In FY 1984, the Administration would eliminate the program and make it part of a block grant. We urge the Committee to support the program at the FY 1981 level of $5.6 million which will fund about 600 trainees and some 60 teaching grants.

For the past decade, this training program has been training support for social work education in the child welfare area. It is the only such support which exists. Support has decreased from a high of about $9 million to $3.8 million. In FY 1983, HHS will minimize further the grants of social work by making any programs eligible to compete. Social work has been the core discipline in child welfare, however. We urge the Committee to provide that the child welfare training funds are intended primarily to train social workers for the child welfare field.

In FY 1982, the OHDS supported child welfare resource centers. These centers are continued in the FY 1983 budget. At least 10 regional centers are being supported and they provide inservice training, research and technical assistance to the state and private child welfare agencies. We interpret the general reduction in the OHDS discretionary project budget to eliminate these centers in FY 1984. The centers are an important part of the child welfare, foster care and adoption system and should not be terminated. We recommend that the child welfare resource program be maintained at its current level.

Social Science Research

We are very pleased by the proposed increase in the NIMH research budget for FY 1984. We believe that NIMH has been encouraging social science research as well as basic research. We appreciate and continue to support the Committee's approach reflected in the FY 1983 Committee Report which encourages social science research at NIMH and which has emphasized the importance of contributions from all disciplines. Likewise, we continue to support the FY 1983 Committee Report provision indicating the importance of encouraging research from all four of the mental health disciplines through eligibility for research training funds.

We are particularly concerned about the special priority which research regarding mental illness among minorities should hold. In FY 1984 the NIMH proposes to support studies to design special treatment methods to reflect knowledge gained about the uniqueness of problems of minorities and ethnic groups. NIMH also needs to conduct comparative research on the major methods of providing treatment, particularly in the community setting, and on treatment provided by various disciplines, either independently or in a team approach. In the past decade there has been a continuous increase in the staffing of Community Mental Health Centers by psychiatric social workers. Despite the diversity of staffing patterns in the centers and approaches to treatment, little research has been done to assess the effectiveness of the different service methods.

Our second concern is that social workers' participation in the mental health service system has been primarily as practitioners. Their role as researchers is not well recognized nor fully appreciated. Increasingly, however, their contributions as researchers must also be given greater attention. The character of their training includes both generic social work education as well as social and behavioral science research. Social work researchers are qualified to conduct research on the following: (1) the special characteristics and problems of minorities, the aged, and the chronically mentally ill; (2) the external stressors in the social and physical environment on emotional and mental disorders and the relation of these factors to individual and family functioning; (3) the relation of the cultural background factors to treatment; and (4) the overall design and evaluation of service delivery systems.

In this connection, we would urge that research and research training programs continue to be provided for those in fields of social and behavioral science, including researchers in the social work discipline.

STATEMENT OF JAMES HOWE, CHAIRMAN, FINANCE COMMITTEE, NATIONAL ALLIANCE FOR THE MENTALLY ILL,

ACCOMPANIED BY CAROL HOWE

Senator PROXMIRE. Our next witness is James Howe, chairman of the finance committee, National Alliance for the Mentally Ill. Mr. Howe, we're happy to have you with us.

Mr. HOWE. If I may bring my wife to the table.

Senator PROXMIRE. Yes, indeed. Delighted. It brightens up the table.

Mr. HOWE. Mr. Chairman, we're Carol and Jim Howe, the parents of four adult children, two of whom are afflicted with severe mental illness. Like many other people in this room, last night we watched the parents of John Hinckley in a very touching interview with Barbara Walters. Those courageous people were trying to give a message to America; what they failed to tell the tens of millions of people who have mental illness in their family, and I might have told them, is that there is an organization that can help bewildered, confused people like that and can give them practical guidance. That organization is the National Alliance for the Mentally Ill. It is a 4-year-old organization. It consists of families and friends of persons with chronic mental illness. It is a self-help group whose members have come out of the closet to advocate for the seriously mentally ill persons who can't advocate for themselves.

We have 200 affiliates in almost every State in the country and we're growing rapidly.

And our immediate recommendations for this committee focus on research, research training and community support programs. The schizophrenias and affective disorders afflict 10 million people in our country. An additional 30 million immediate family members are impacted by these disorders. In fact, of the total hospital beds in our Nation, more are occupied by the mentally ill than by those with any other disease. The schizophrenias alone cost this country $20 billion a year and the manic depressive illness almost another $20 billion.

We know today that serious mental illnesses are biochemical in origin and the research on the brain and associated physical systems is crucial to find causes and treatment approaches. As a Nation, we declared war on cancer, heart disease, diabetes, and other killing diseases, yet more persons are incapacitated by severe mental illness than by any other disease. The budget for cancer research is about $1 billion, for heart research is approaching $500 million, but the proposed research for all mental illness is only $172 million.

In other terms, the Federal Government spends $203 for every person with cancer and only $7 for a person with schizophrenia. We're distressed that grant funds for NIMH research for the past 1½ years have been reduced by 5 to 15 percent. More, not fewer funds to research mental illness is imperative.

It's time now for the Federal Government to appropriate additional funds for research in direct proportion to the number of severely mentally disabled people in the country. It's time now to declare war on severe mental illness. The budget now being proposed is totally inappropriate to such a full declaration of war. Over the next few years, we must adjust our sights to much larger budgets. Meanwhile, as a first and only very partial step, we recommend that this committee increase by $11 million funds for research on the schizophrenias and affective disorders. New computerized technology, the CAT scan and now the PETT scan and new biochemical clues, place us at the threshold of new discoveries. The time is right for a major research effort.

A corollary to research is research training. It takes 5 to 8 years to develop a good researcher, yet the funding for research training is $3.4 million less than in fiscal year 1982. We recommend an additional $5 million for research training to attract and retain bright young scientists.

I turn now to the community support program which has encouraged States to increase their support for the chronically mentally ill by $18 for each Federal dollar and help States build better community support delivery systems. One result is that hospitalizations are down by 50 percent. We recommend an appropriation of $14 million for this program in fiscal year 1984.

Mr. Chairman, it is time for America to recognize the magnitude of its problem of mental illness and to bring its best talents into the battle against this scourge, strengthening its scientific research to find the cause and treatment for the disease and building effective community support to permit its victims to lead decent lives while a search for a cure goes on.

We have a hope for a better future for our fellow citizens. We look to you to fulfill our hopes and to make them into realities.

And that ends my statement. If I could, Mr. Chairman, I would like to present for inclusion in the record, four short letters that the National Alliance for the Mentally Ill has received which spell out the kinds of research that are needed.

[The information follows:]

LETTER FROM ROBERT CANCRO, M.D., PROFESSOR AND CHAIRMAN, NEW YORK UNIVERSITY MEDICAL CENTER

April 11, 1983

Mr. Bernard Smith
Executive Director
National Alliance for Mentally Ill
1234 Massachusetts Avenue, N.W.
Washington, D.C. 20005

Dear Mr. Smith:

The Analytical Psychopharmacology Laboratory at Rockland Research Institute under the direction of Thomas B. Cooper has been, and is, directly involved in developing procedures for the improvement of pharmacotherapy in the mentally ill. This laboratory has developed analytical methodology for the analysis of psychotropic drugs and psychoactive metabolites in plasma of treated patients. Many of these techniques are now routinely used in clinical laboratories across the country. A number of the programs that are currently being carried out in the laboratory are under Federally supported grants.

Other programs that are supported through state and private agencies are directed toward the same goals--improved delivery of services for the mentally disabled with a decrease in cost to the patient. In the past, this laboratory has prepared and executed FDA approved protocols demonstrating the equivalence of generic formulations of psychotropic drugs such as Thorazine, Tofranil and Librium which has has already resulted in major cost reductions to the state in medication purchases. Current protocols will examine Mellaril and Stelazine which should result in even further savings.

When blood samples are required for drug monitoring this presents major problems in the treatment of the very young and the elderly: e.g., blood sampling is not well tolerated in these groups and may result in patient refusal to accept treatment. A possible alternative approach is to monitor saliva samples instead of blood. Our preliminary published data indicate that this procedure holds great promise in antidepressant therapy and work is underway examining the high potency neuroleptic drug Haldol.

The development of new analytical methodology for the routine determination of psychotropic medication in biofluids would provide a major incentive for measurement in clinical practice which should lead to these drugs being used more effectively, reducing patient suffering and costs and in the cases of indigent patients within state and Federal systems reducing costs borne by the public-at-large.

The Information Sciences Division of Rockland-NYU applies computers to the problems of clinical practice. The quality of care the estimated 138,000 psychiatric inpatients in the United States receive cannot be allowed to revert to the low levels that precipitated the court decrees of the late sixties and early seventies. Computer technology has been adapted for the administrative and clinical management of mental hospitals (for example, a drug prescription monitoring system that compares the medication combinations and dosages for every prescription written in a facility to guidelines developed by psychiatrists who are at the forefront of research in psychopharmacology). The review system has been incorporated into the ongoing peer review process in study facilities by requiring a justification for any combination or dosage that does not meet the specifications of the therapeutic manual. This system has been shown to significantly reduce the numbers of orders written in exception to the guidelines in state facilities for the mentally retarded and mentally ill.

The cost and effectiveness of a comprehensive network of mental health services for major psychiatric diagnostic groups in a suburban county have been studied with particular focus on severe alcoholics. Although alcoholics consumed minimal costs in this service system, half of the alcoholic study population was readmitted to inpatient care during a two year follow-up. Contrary to much of the current literature, our results indicate that the receipt of outpatient services increases a patient's ability to function outside of the hospital. A statistical methodology adapted from the area of cancer research is now being used to identify the service patterns most effective in preventing recidivism.

Tardive dyskinesia (TD) is a serious and relatively permanent side effect of neuroleptic treatment. It is marked by involuntary movements of the facial muscles, the tongue, the trunk and extremities. Muscles involved in respiration are also frequently affected, which adds to the seriousness of this condition. The prevalence of TD among chronic psychiatric inpatients is approximately 30%, which makes it a very major public health problem. The mechanism of TD is incompletely understood, and no satisfactory treatment is available.

The work of Rockland and NYU at the Manhattan Psychiatric Center (MPC) has been concerned with the understanding of basic TD mechanism as well as with its treatment. It had been reported that dietary enrichment with lecithin reduces the severity of TD, but our studies have disconfirmed those early observations. There were, however, theoretical reasons to expect TD improvement if lecithin is administered concurrently with lithium. We have conducted a preliminary experiment testing the efficacy of this new combined treatment, and found that it did indeed significantly reduce the TD movements. These new findings need replication in a larger patient sample.

As we were exploring the effects of lecithin enrichment on TD, we launched a series of subsidiary studies. THese included a study of the safety of lecithin (a matter of public health, since the use of lecithin dietary enrichment is widespread), and a study of lecithin effects on brainwaves (EEG).

We have also been studying the possibility that endorphins play a role in the development of TD. Injections of naloxone, a specific opiate antagonist, did not have any effect on TD, but they elicited a number of changes of the hormones in the patients' blood; we are pursuing the findings further.

To visualize the brain changes underlining TD, we are beginning to utilize the latest development in the brain imaging technology--the Positron Emission Tomography. Patients with TD are subjected to this painless examination before, during, and after the treatment with lithium and lecithin. We hope to shed some light on the mechanism of TD using this most advanced technique.

The PET (positron emission tomography) program is a pioneering effort involving scientists and physicians from several institutions in an effort to better understand how the human brain functions in health and disease. The technique involves the administration of a trace quantity of a labeled substance which is of significance to brain function. This substance may measure the functional activity of regions of the brain involved with thinking, or emotion or integration of these elements as well as those regions reflecting physical activity. Alternatively, we have begun to study the distribution of tranquilizers and other psychoactive drugs in the brain. We are combining these approaches by studying the effect of these drugs when used in the treatment of psychiatric illness. Much of our effort has concentrated on determining the characteristics of altered brain metabolic functioning in psychiatric conditions of great social consequence including Alzheimer's disease, schizophrenia, and depression. Preliminary results suggest that there are patterns of metabolic activity that may be of diagnostic significance and be of special importance in assessing the effects of treatment and in developing new treatments.

These PET images, which are biochemical CT scans, already have shown that biochemical changes in the brain associated with treatment correspond to clinical improvement. Although it is yet too soon to be dogmatic, it appears that these studies will lead to better diagnoses, new and better drugs, a better understanding of the relationship between physical and psychiatric illness, and, ultimately, better patient care.

Sincerely yours,

Robert Cancro, M.D.
Professor and Chairman

LETTER FROM RONALD R. FIEVE, M.D., CHIEF OF PSYCHIATRIC RESEARCH, DEPARTMENT OF LITHIUM STUDIES; PROFESSOR OF CLINICAL PSYCHIATRY, COLUMBIA UNIVERSITY

31 March 1983

Mr. Bernard Smith
Executive Director
National Alliance For The Mentally Ill
1234 Massachuetts Avenue, N.W.
Washington, D.C. 20005

Dear Mr. Smith:

I am writing to you at the request of the Parents Group of the New York State Psychiatric Institute on what I think are extremely important areas in the fields of psycho biology and psychopharmacology requiring Federal funding over the next decade.

I will speak specifically on the fields of affective disorders, depression and manic depression; as well as on their treatments: the antidepressant agents and lithium carbonate for which I am intimately associated with and have been personally researching over the last 25 years.

In one sense, one hardly need to defend the argument for the value of biological, psychobiological and psychopharmacologic research when one looks at the track record that funding in these two related fields have accomplished since 1957. Accomplishments include:

1) a great improvement and agreement in psychiatric diagnosis;

2) the establishment of lithium as a major treatment and prophylactic agent in manic depression;

3) the development and establishment of a number of tricyclic and MAO-inhibitor agents for treating the major depressive disorders in both the unipolar and bipolar phases;

4) an understanding of the genetic transmission and the environmental contributions to manic depression, schizophrenia and other psychiatric disorders;

5) investigations into the basic mechanisms of action of lithium, and other psychotropic drugs;

6) as well as an understanding of neurophysiological systems in the human as well as animal.

7) in all of the above, promising early advances in childhood and adolescent affective disorder research is being accomplished.

The overall significance of these major breakthroughs in psychobiology and psychopharmacology over the past 25 years have resulted in the relief of human suffering, and fruition of normal lives for millions of people who previously had been incorrectly diagnosed or inadequately treated.

The cost-effectiveness of applying the new and appropriate treatments to the correct diagnoses in this country alone probably results in billions of dollars in savings; clearly, when the new lithium clinic/depression clinic, or drug clinic model is applied to affective disorders in the community.

With the above track record, one hardly need justify to any government body the necessity to continue this kind of research into the psychobiology of affective disorders and other psychiatric disorders.

During the next few years, the major thrust in research should be aimed at the psychobiology (environmental, genetic, biological and sociological components) of affective disorders. This, in turn, must be paralleled by basic research in the laboratory aimed at unravelling the underlying chemical and physiological mechanisms of action of the agents being developed. In addition, further investigation into the psychosocial components of the illness, transmitted genetically/environmentally, should be pursued. Such discoveries would revolutionize even further the treatment of affective disorders whereby reducing human suffering for millions of people and reduce the debt to society which goes into the billions.

In conclusion, research, both basic and clinical, in the mental health field and most specifically in affective disorders, is one of the best stocks for all agencies and citizens to invest in during the 1980s. To overlook such promising area of research would be a grave error both in terms of long-range financial burdens and in terms of human productivity permitted by advances in mental health research.

If I could be of further assistance to you, please do not hesitate to contact me at (212) 960-5882.

Sincerely yours,

Ronald R. Fieve

Ronald R. Fieve, M.D.
Chief of Psychiatric Research,
Department of Lithium Studies;
Professor of Clinical Psychiatry,
Columbia University

Letter From Fritz A. Henn, M.D., Ph. D., Professor and Chairman, Department of Psychiatry and Behavioral Science, State University of New York at Stony Brook

March 31, 1983

Mrs. Agnes Hatfield
President
National Alliance for Mentally Ill
1234 Massachusetts Avenue N.W.
Washington, D.C. 20005

Dear Mrs. Hatfield:

This letter is to support your efforts at the National Alliance for Mentally Ill to obtain research support into the nature and treatment of chronic mental illness. Research has been credited with the medications which made deinstitutionalization possible. While this has resulted in some improvement in care and a real cost saving to society, it represents only the first step in our battle against mental illness. The medications we currently have do not cure schizophrenia or affective disorders. We have no effective treatment for antisocial personality which fills our prisons. Thus, much remains to be done.

Currently in my state, New York, the hospital rates are going up, more people are in need of institutional care this year than last. This reflects the real limitations of our current treatments especially for schizophrenia. This disease affects about 1% of the population, however, the costs in human suffering and dollars is staggering. The illness strikes young adults and persists throughout a patient's lifetime, often for over forty years. Thus, the cost of care is enormous as is the toll on families having an affected member. In this disorder, the principal drugs tend to produce severe motor disorders in some patients if used chronically. Of course, chronic use is just what is often necessary. Thus, new approaches are desperately needed.

New approaches are being developed. Our understanding of schizophrenia as a real illness with biological mechanisms is becoming clarified. I recently was involved in collecting this information in one volume (Schizophrenia as a Brain Disease, Oxford University Press), and it is exciting to see real advances in our understanding emerge which are based on solid work in the neurosciences. We stand close to the next major step in schizophrenia research and for our sake as a society, and for the sake of our patients, this work must go on. More nurses, aides and hospital beds will drain our budgets and not really change the lives of our patients. Research is the only alternative, support here will ultimately alter the course of these disorders, and our patients' lives. The cost of heart disease or cancer is large, schizophrenia may well be larger when the duration of the illness is considered. Research is the area of mental health that deserves an equivalent priority.

Best wishes in your efforts.

Sincerely,

Fritz A. H

Fritz A. Henn, M.D., Ph.D.
Professor and Chairman

STATEMENT OF L. ERLENMEYER-KIMLING, PH. D., DIRECTOR, DIVISION OF DEVELOPMENTAL BEHAVIORAL STUDIES, OFFICE OF MENTAL HEALTH, NEW YORK STATE PSYCHIATRIC INSTITUTE

In this longitudinal study, a large group of collaborating investigators has been following children of schizophrenic, depressed, and normal parents from mid-childhood through adolescence. Children of mentally ill parents are at high risk for developing mental disorders themselves during adolescence or young adulthood: 10 - 15% of children with one schizophrenic parent and 35 - 40% of children with two schizophrenic parents may be expected to develop schizophrenic disorders at some time during their lives. Risks for depression are similar or possibly higher in the children of one or two depressed parents.

One of the main objectives of the multidisciplinary study is concerned with early identification of those children of mentally ill parents who are most likely to manifest schizophrenia or depression later in life. Thus, the research program is expected to provide both the means of identifying children who need early preventive intervention and important insights into the types of intervention that will be useful with such children. It is important to note that the majority of people who become schizophrenic or depressed do not have a mentally ill parent and that the establishment of objective means for identifying children at risk at young ages is therefore essential for ensuring that these children will be accessible to preventive efforts.

Two independent samples of children are being studied. Children in both samples were initially between the ages of 7 and 12 and were considered to be psychiatrically normal. The first sample, consisting of 208 children, has been followed since 1971 and has been examined on four separate occasions at intervals of two to three years to enable the investigators to track the course of both normal and deviant development. A second sample of 150 children was added in 1977 in order to evaluate the replicability of findings on the first sample. The second sample has now been examined twice and is shortly due for a third examination.

Each examination has consisted of a home interview with the parents and children and administration of a number of measures in the Laboratory, including: psychophysiological recordings of brain electrical activity; a neurological examination; measures of vigilance, attention, distraction and reaction time; perceptual and IQ measures; videotaped psychiatric interviews; and social adjustment and peer-relations inventories. School record data and teachers' evaluations are also obtained on each child. Interim follow-up information is received through regularly scheduled telephone contacts every six months.

While a number of the measures under investigation have been found to differentiate children of schizophrenic parents from children of depressed or normal parents, a particularly striking finding relates to subtle attentional dysfunctions, as measured behaviorially by electrical activity of the brain. These occur at young ages significantly more often in a subgroup of the children of schizophrenic parents than in the other two groups. Moreover, there is a highly significant correlation between early attentional dysfunctions and the emergence of psychopathological conditions in adolescence among the children of schizophrenic parents, but no such relationship at all in the other two groups. Thus, attentional dysfunctions of a relatively subtle nature between the ages of 7 and 12 may well be indicators of a susceptibility to the development of schizophrenic disorders. If this result is replicated in the second sample, it will be possible to devise intervention strategies directed at controlling attentional difficulties and, possibly, at decelerating the process of becoming mentally ill.

Finally, over the course of the investigation, project staff has provided services in the form of advisory screening, referrals, and supportive therapy to the families participating in the study. This part of the project is providing systematic assessment of the needs of the children of mentally disturbed parents during the children's school and adolescent years, the availability of resources to meet these needs, the effectiveness of contact with such resources, and the value of a service function within the framework of high-risk research.

It should be mentioned that any hiatus in funding that might have led to an interruption of the study during the children's developmental years would have severely handicapped the results.

STATEMENT OF JAMES HOWE

I am James Howe, the father of four adult children two of whom are afflicted with severe mental illnesses. I speak for The National Alliance for the Mentally Ill, an organization almost four years old, consisting of family members - parents, spouses, siblings, children - and friends of individuals with severe, chronic and disabling mental illnesses - the schizophrenias and affective or manic depressive disorders.

We are a self-help organization whose members have come out of the closet to advocate for the seriously mentally ill who are unable to speak on their own behalf. Also, we provide mutual emotional support to families struggling with these dreaded illnesses. We support and educate each other in coping and managing the effects of the illness on the mentally sick relative and its impact on the total family. The National Alliance for the Mentally Ill has 200 affiliates in almost every state in the country, and we are growing rapidly.

Our immediate recommendations for this Committee focus on research, research training and the Community Support Program.

The schizophrenias and affective disorders affect 10 million people in our country. An additional 30 million immediate family members are impacted by these disorders - by repeated crises including hospitalizations, suicides, inability to maintain jobs in competitive settings, and difficulties in relationships.

Of the total hospital beds in our nation, more are occupied by the mentally ill than those with any other illness. The schizophrenias alone cost this country at least $20 billion a year, and the manic-depressive illnesses close to another $20 billion a year. These disorders cause more prolonged morbidity and crippling social and economic dysfunctions than any of the physical diseases or the emotional and situational distress neuroses--the mental health problems as contrasted with the serious psychoses. We know today that the serious mental illnesses are biochemical in origin, frequently with genetic predispositions, and that research on the brain and associated physical systems is crucial in unravelling the specific causes and treatment approaches.

As a nation we declared war on cancer. We declared war on heart disease, diabetes and other killing diseases. Yet, more persons are incapacitated by crippling severe and long-term mental illnesses than by any other disease. The research budget for cancer research is about 1 billion dollars, heart research is approaching one half billion dollars, yet the proposed research for all mental illness is only $172 million, far from adequate. In other terms, the federal government spends $203 per year for every person who has cancer, and only $7 for a person with schizophrenia.

We are distressed that grant funding levels for NIMH research for the past one and a half years have been reduced across the board by 5 to 15 percent. Research on the severe mental illnesses is operating at less than full capacity with good solid neuroscience and clinical research opportunities going unfunded. In fact the score (pay line) currently for funding NIMH research proposals has reached an unprecedented level from 140 to 160 where 100 is perfect and proposals may range as high as 500.

More funds to research the major mental illnesses is imperative. For example, NIMH has been unable to fund a biochemical multicenter to provide the very best research techniques and to pool the knowledge gained from research breakthroughs anywhere in the consortium so as to add strength to the individual studies of each participant. Such research is expensive, yet must be supported to alleviate the sufferings of severe mental illnesses.

Forty years ago, cancer was a dreaded disease with few if any cures and little knowledge as to causes. Patients with cancer were not mentioned by family members as it brought a certain stigma upon them. Since then, work by a variety of scientists has resulted in methods for treatment and cures for some types of cancer.

It is time now for the federal government to come out of the closet and to appropriate additional funds for the NIMH research in direct proportion to the number of severely mentally disabled people in the country. It is time now to declare war on severe mental illnesses. The budget now being proposed is totally inappropriate to such a full declaration of war. Over the next few years we must adjust our sights to much larger budgets. Meanwhile, as a first and only very partial step, we specifically recommend that this Committee increase the NIMH proposed extramural research appropriation by $11 million, and that these additional funds be directed exclusively for research on the schizophrenias and affective disorders. This would increase the total NIMH research budget from $172,133,000 to $183,133,000.

Family members and advocates, as well as scientists, understand that the only real prevention for major mental illnesses is research into its causes and treatments. The only way to eliminate the stigma connected with the serious mental illnesses is research that effects cures. We are at the threshold of scientific breakthroughs, of expanding scientific understanding of the serious mental disorders. The new computerized technology, the CAT scan and now the PET scan, and new biochemical clues place us at this threshold.

A corrolary to research is research training. It takes 5 to 8 years to develop a good researcher. Yet the funding for research training has remained almost constant for the past three years, seven percent of the total NIMH budget, and $3.4 million less than in 1981. We recommend an additional $5 million for research training to attract and retain young bright scientists. Leadership is vital to insure a sustained and continuing research effort.

Dr. William Mayer, administrator of ADAMHA, testified previously to the efficacy of the Community Support Program that has reduced hospitalizations by 50%, increased state support for the chronically mentally ill $18 for each federal dollar, and restructured state and community delivery systems to focus and coordinate services on their behalf. Thirty nine states are now receiving modest Community Support Program grants. Of these, 20 states were funded for the first time late in FY 1982. An additional six to ten states will receive funds this fiscal year. The art of improved delivery systems for the chronically mentally ill is not so readily transferable as scientific knowledge. Each state requires a five year demonstration period to mobilize and coordinate its own efforts on behalf of persons recovering from major mental illnesses.

Congress in its wisdom and good judgement has continued this program the past two years. We recommend an appropriation of $14 million for the Community Support Program in FY 1984. This will permit continuation grants to 33 states and starts for an additional 6 states or territories. It also will allow 12 new project starts for seriously mentally ill children and adolescents, whose problems are different from those of the adult chronically mentally ill. Applied research into the structure, operations and impact of the mental health delivery system on the chronically mentally ill will be continued as will limited research into the homeless population.

We support the Alcohol Drug Abuse and Mental Health Block Grant level of $439 million. However, we request Congressional monitoring of this sum, to determine if in fact Community Mental Health Centers are indeed serving the seriously and chronically mentally ill as repeatedly mandated in previous appropriations conference reports.

It is time for America to recognize the magnitude of its problem of mental illness and to bring its best talents into the battle against this scourge, strengthening its scientific research to find the cause and treatment for the disease and building effective community support to permit its victims to live decent lives while a search for a cure goes on. We have hope for a better future, for our loved ones. We look to you to fulfill our hopes and to make them into realities.

Senator PROXMIRE. Thank you very much, Mr. and Mrs. Howe. Where are you from, sir?

Mr. HOWE. We're from Garrett Park, Md.

Senator PROXMIRE. Garrett Park, Md.

Mr. HOWE. And you and I went to Harvard together.

Senator PROXMIRE. Is that right?

Mr. HOWE. Yes.

Senator PROXMIRE. I thought there was something special about you. [Laughter.]

Mr. HOWE. Well, our main contact, however, has been when you went chugging by me. I worked at 1717 Massachusetts Avenue for 10 years, and almost every morning I saw you run by. [Laughter.]

Senator PROXMIRE. Well, you're a remarkable couple, and you certainly deserve the gratitude of the Congress for doing this, particularly with your own very, very serious and painful problem. And I was delighted the way you led off. It's too bad we can't have a full committee here, with your reference to the Hinckley tragedy. It certainly drives home the point, I think, to all of us. I didn't happen to see that last night, but I can get a transcript of it. But it was a very, very effective statement. We are most grateful to you. And thank you very much.

Mr. HOWE. Thank you.

STATEMENT OF DR. JOHN H. JACKSON, CHIEF, DEPARTMENT OF PSYCHOLOGICAL SERVICES, MILWAUKEE PUBLIC SCHOOLS, ASSOCIATION FOR THE ADVANCEMENT OF PSYCHOLOGY

ACCOMPANIED BY CLARENCE MARTIN, EXECUTIVE DIRECTOR, ASSOCIATION FOR THE ADVANCEMENT OF PSYCHOLOGY

Senator PROXMIRE. Our next witness is Dr. John Jackson. Dr. Jackson is the chief, department of psychological services, Milwaukee Public Schools.

Yesterday, I had a nice conference with Lee McMurrain.

Dr. JACKSON. You did?

Senator PROXMIRE. Yes, indeed.

Dr. JACKSON. Well, I left things in good shape yesterday. I hope I find them that way when I get back tonight.

Senator PROXMIRE. Very good.

Dr. JACKSON. Thank you, Senator.

Psychologists have several major concerns about appropriations for the National Institute of Mental Health. First is that funds continue to be available for vital research into the causes and treatment of mental disorders.

Senator Proxmire, we fully support the NIMH research budget proposal of $172 million. However, we are concerned about the administration's severe restrictions on the funding of social research.

We believe these restrictions violate NIMH's mission, which calls for the broadest possible participation of medicine science to social sciences and related disciplines.

As economic conditions have gotten worse, the number of our citizens with mental and emotional disabilities have increased. More information is needed to help policymakers assess the effects of difficult policy decisions on individuals.

Yet important research on such topics as unemployment, inadequate housing, divorce, and criminal behavior is not allowed under current policy. We urge the committee to reverse this administration's policy.

Another concern is that funds continue to be available for research training. We fully support the aims of the NIMH research training program and urge this committee to restore the funds to the 1981 level of $19.5 million.

The research training budget was reduced to $15.4 million in the last 2 years, and the result has been drastic reduction in the number of students supported, from over 1,350 students in fiscal year 1980 to a projected 880 students in fiscal year 1984. We caution that some areas of research may need a full decade to rebuild if a critical mass of young scholars is lost now.

A major concern that we have is clinical training of mental health professionals, and we have three requests of the committee in this regard.

First and foremost, to continue the NIMH clinical training program.

Second, to mandate greater use of the payback requirement as a way of getting care for underserved populations.

Third, to require that funds be distributed more evenly among the four core mental health professions.

Specifically, we ask that clinical training be restored to the fiscal year 1982 level of $42.2 million.

NIMH has calculated that there is a present need for 91,000 practitioners in each of the four core mental health professions. As of 1980, they could count only 44,800 psychologists, 38,700 psychiatrists, 36,600 social workers, and 51,300 nurses.

Additionally, the need for trained personnel to treat underserved populations is well documented, and it is often tragic. For instance, the National Coalition for Jail Reform reports that there are fewer than 10 jails in the entire country that have any mental health personnel available to treat disturbed arrestees or prisoners.

One-half to three-quarters of nursing home residents suffer from significant degrees of mental impairment, but only a very small fraction of all patients living in nursing homes have access to treatment by a mental health professional.

According to the children's defense fund, of the 3 million seriously mentally disturbed children in the country, two-thirds are not getting the services they need, and countless others are getting inappropriate care.

Although there are 54 million people in rural America, there are now only four psychology programs offering substantial training in rural mental health.

The lack of relevant mental health services for minorities is widely acknowledged, and this committee has supported the NIMH minority fellowship program strongly in the past. Your continued support for clinical training to serve minority populations is most important.

NIMH also reports that advances in the treatment of the chronically mentally ill have increased the need for psychologists trained to work in inpatient facilities and in community settings for deinstitutionalized patients.

Because of all these needs, we urge this committee to require that NIMH use its clinical training funds to produce fully trained mental health professionals for the delivery of services to unserved and underserved populations.

Specifically, we urge you to request that no more than 25 percent of the clinical training funds be used to support trainees who will not have a payback obligation to deliver mental health services to these populations.

We further urge you to require that NIMH fund each of the mental health disciplines in an equitable balance so as to produce the best possible range of practitioners and approaches available to deliver services.

In closing, Senator Proxmire, I would like to add three brief points.

First, we are studying the implications of the administration's proposal for placing St. Elizabeth's Hospital in a public corporation. I would like permission to submit an additional statement on the future of this important national asset prior to the closing of the record on these hearings.

Senator PROXMIRE. Yes; when will you be able to give us this additional information?

Dr. JACKSON. We would be able to get it in prior to the closing. Do you have an idea when you will be closing the hearings?

Senator PROXMIRE. May 6.

Dr. JACKSON. We would have it in prior to May 6.

Senator PROXMIRE. All right.

Dr. JACKSON. But we need time to develop a very balanced statement.

[The information follows:]

STATEMENT OF THE ASSOCIATION FOR THE ADVANCEMENT OF PSYCHOLOGY

The emphasis of the administration's testimony continues to be the "financial self-sufficiency" of St. Elizabeths Hospital. We appreciate the administration's announcement that "considerable progress has been made in the area of patient care financing." We are concerned that the real issues should be first of all the quality of care for patients in St. Elizabeths. Second, we believe a determination of the status of St. Elizabeths, which ADAMHA Administrator Mayer describes as a "precious national resource," as a national institution needs to be made.

Again this year the administration has proposed to unveil at some uncertain future data a public, or quasipublic, corporate structure to govern and manage St. Elizabeths. These vague proposals are presented at the same time that we see newspaper articles suggesting that the treatment facilities may be moved to another site and that the present location may be sold to private investors as a choice real estate development.

St. Elizabeths is a unique, historically significant institution serving the District of Columbia, Maryland, and Virginia and especially providing services in the highly underserved area of Anacostia. It is staffed by exceptional and azygos personnel in both its clinical and research activities. It does not seem unreasonable that such an institution should receive Federal subsidization and protection from commercial intrusion equal to that of any other significant monument in this Capital city and that its staff should not suffer annual threats of being shifted from one governmental authority to another.

We support the proposed budget of $143.5 million for fiscal year 1984.

The increase of the District of Columbia's share of the fiscal year 1984 program budget is totally unreasonable. $3.3 million is being charged to the D.C. government for startup costs for the proposed corporation. This is simply not the financial responsibility of the District of Columbia.

Nine million dollars is being charged for increased participation in inpatient costs at the same time the administration states in the testimony before this committee on April 14, 1983, that it has shown:

(1) An 11-percent reduction in the rate of rehospitalization for outpatients;

(2) An 8-percent increase in admissions of patients screened by the intake unit;

(3) A reduction in the average length of stay from 16 days to 11 days;

(4) A drop in the inpatient census by approximately 6 percent since last year.

A $15.4 million increase is being charged for care delivered District residents who do not require acute psychiatric care but require nursing care. This is clearly a Federal obligation until such time as the management of St. Elizabeths, or at least the nursing facility, is clearly transferred to the District of Columbia.

We urge this committee to appropriate the full $143.5 million to St. Elizabeths; to maintain the District of Columbia's contribution at $38.8 million, rejecting the additional $29.9 million increase; to once again urge the administration to assume full and active responsibility for the hospital, its staff and the quality of care of its patients until a definitive agreement can be negotiated on the future of this "precious national resource."

STATEMENT OF DR. JOHN H. JACKSON

We have submitted separately to this Committee testimony on Mental Health Appropriations. The following testimony deals with other areas within HHS and Ed.

NATIONAL INSTITUTES OF HEALTH (NIH)

This Committee has been a source of strong support for the 14 Institutes that comprise the NIH. Below are descriptions of programs and issues within NIH that are of interest to psychologists as behavioral and social science researchers.

Prevention

Behavior is a key factor in prevention activities. The Surgeon General's report, Healthy People, examined the 10 leading causes of death in the United States and concluded that 7 are in large part behaviorally determined and could be substantially reduced by individuals changing their behaviors. Thus, we need to solidify the role of behavioral and social science in federal health research programs.

Legislation has been introduced in both houses of Congress that would establish a stronger Prevention component within NIH. Although the specifics of these bills differ, it is clear that support exists for creating a greater institutional presence for prevention, as well as increasing support for research on prevention-related issues. We support the establishment of high-level offices for Prevention in NIH, with an increased advisory role for behavioral and social scientists.

Research and Training

NIH told Congress that in FY 84 research projects will "continue to receive the highest priority because they are acknowledged as the primary means by which fundamental discoveries emerge." However, without a budget increase from Congress, there will be a decline in the number of projects supported by NIH. It is projected that the FY 84 budget request would support only 3,676 new and competing research project grants, and 11,560 noncompeting awards, so that the total number of new and noncompeting grants supported will be 15,236. This is 1,121 fewer grants than in 1983.

Research training is also declining at NIH. The FY 84 budget request would support only 9,100 trainees, down from 9,969 in FY 83, and is almost a 10% reduction in support. In addition to reversing this decline in the number of trainees, we ask that Congress monitor NIH policies that establish the proportion of pre-doctoral versus post-doctoral training awards that are made. Advanced training in psychology and the other behavioral sciences has always focused on the pre-doctoral level. Attempts to shift training funds to the post-doctoral level may seriously endanger the many advances in behavioral research that we point out later in this testimony.

Primate Research Centers

There are seven Regional Primate Research Centers being funded through the NIH Division of Research Resources. The FY 83 authorizations for the Centers is $19.3 million, and a budget request of $20.3 million has been submitted for FY 84. These funds are an investment in developing critical resources for the nation's biomedical and behavioral research enterprise. They will have profound implications for efforts to increase understanding about such human maladies as kidney disease, leprosy, cystic fibrosis, visual disorders, blood disorders, and fetal development, as well as a host of other conditions. We strongly urge you to support full funding of this program.

Public Health Emergencies Research

We strongly urge Congress to earmark funds, as it did last year, for "fast track" research awards in the causes, diagnosis and treatment of new diseases and disorders which constitute a public health emergency, such as AIDS (acquired immune deficiency syndrome), toxic shock syndrome, and Legionnaires disease.

National Institute of Child Health and Human Development (NICHD)

The National Institute of Child Health and Human Development (NICHD) is the lead Institute at NIH for support of behavioral and social science research. Approximately one-fifth of its extramural funds are allocated for research on behavioral factors that contribute to the development of infants, children, adolescents, and their mothers. In recent years, research supported by NICHD has led to significant advances in our understanding of both normal and abnormal development. Such understanding is vital to assuring that our nation's children have sound and healthy early years, thus reducing the need for costly programs later on.

The Administration has proposed a 1.5% increase in the NICHD budget for FY 84. Extramural Research programs would increase only about .6% above FY 83. In the past, the Congress has supported increases for NIH over the Administration's proposals. We urge you to continue that tradition which recognizes the contribution of national research activities as a wise investment in the health and well-being of our citizens. The vital research supported by the NICHD merits, at the minimum, an increase of 5% over FY 83 appropriations.

National Institute on Aging (NIA)

While the President's proposed FY 84 budget for NIA calls for a slight increase over the FY 83 funding level (from $94 million to $95.7 million), inflation results in a net decrease for NIA programs. This erosion of support is particularly detrimental in light of recent funding decreases for behavioral and social science programs in the NIA Intramural Program, and in view of reductions in the FY 84 Administration on Aging budget, where the President has proposed a 77% decrease in research, training, and new discretionary programs. We, therefore, urge the Congress as a minimum to approve a 5% increase for NIA in FY 84 and to reiterate Congressional support for the important behavioral and social science research undertaken with NIA support.

National Cancer Institute (NCI)

NCI has been slated for only a .6% increase over FY 83 (from $983.6 million to $989.3 million). Within NCI there has been a program of particular interest to the behavioral and social science research community -- the Behavioral Medicine Branch -- which has supported investigations into identifying behavioral factors associated with the cause and treatment of cancer as well as assessments of the broader social impact of the disease. This Branch has been taken as a model by psychologists of the positive role behavior plays in prevention. However, we are concerned about reports that a recent reorganization within NCI has closed the Branch and that Behavioral Medicine activities have been de-emphasized as a result. We do not believe this de-emphasis is in keeping with the sentiment this committee has traditionally expressed.

We urge that Behavioral Medicine research be restated as a mandate for NCI and that budget increases be applied proportionately within activities of NCI, including Behavioral Medicine. We ask that at least a 5% increase be approved for the Institute.

National Heart, Lung and Blood Institute (NHLBI)

NHLBI is directly concerned with four of the ten leading causes of death among Americans: heart disease, cerebrovascular disease, chronic obstructive pulmonary disease (fifth), and arteriosclerosis. NHLBI has within its extramural program a Behavioral Medicine Branch, concerned with basic research into the influence of behavioral factors on the cardiovascular system and other important treatment and prevention techniques, including: techniques to cope with conditions such as hypertension and coronary heart disease; specific interventions that promote compliance with treatment for heart disease; and techniques that promote good health practices in general. We urge Congress to support not only a strengthened budget for this Institute but also the laudable goals it serves, particularly in its Behavioral Medicine Branch.

An FY 84 budget request of $628.0 million has been submitted for the NHLBI. This is a virtual non-increase of $5.3 million over the FY 83 budget. As with the other Institutes, we ask this Subcommittee to appropriate an increase of at least 5% as a step toward alleviating the fiscal constraints of level funding in times of inflation.

National Institute of Neurological and Communicative Disorders and Stroke (NINCDS)

This Institute's extramural research budget consists of two major areas which, combined, are targeted for an FY 84 budget increase of $2.8 million (to $237.8 million in FY 84). Overall, the FY 84 request for NINCDS is $301.0 million, an increase of $5.3 million over FY 83. Both extramural categories -- Biological Basic Research and

Clinical Research -- contain specific lines for learning and behavior. We support the important work being done by the Institute but are concerned that the importance of the contributions of behavioral and social science research have been ignored in the program descriptions accompanying the FY 84 budget requests.

We urge this Subcommittee to support an increase in funding of at least 5% for the Institute, and request that you include concern about the status of behavioral and social science research at NINCDS in your communication with the Institute.

National Institute of Dental Research (NIDR)

Behavioral research is recognized as an important component in addressing pain diagnosis and treatment problems at NIDR. The total FY 84 budget request for NIDR is $80.6 million, which is an increase of $1.7 million over FY 83.

Special emphasis is placed on developing knowledge of "how to produce and sustain preventive behaviors...." The use of a flouride mouth rinse by adolescents and children is just one area being investigated. Dental anxiety is also a continuing issue to the extent that it results in delays or total avoidance of dental treatment. Children's anxiety is of particular concern. We are calling for a 5% increase for NIDR in FY 84, and a renewed commitment to behavioral studies there.

DEPARTMENT OF EDUCATION (DoEd)

We believe there is an appropriate federal role in education, particularly in supporting research and development activities and in providing leadership in areas of national security interests such as science, mathematics, and technology education. The abdication of a federal presence in education negates current thinking among many state governors and executives in the private sector that education is a critical factor in national economic recovery and productivity. We urge the committee to oppose the Administration's proposals to eliminate cabinet-level status for education.

National Institute of Education (NIE)

The National Institute of Education (NIE) is the primary federal agency for the support of research relevant to education. Despite significant achievements, the Administration has only requested $48.2 million for FY 84, a reduction of 13.3% from FY 83 support. This reduction will adversely affect NIE's ability to support new grants and contracts, and will greatly hinder its ability to continue to build upon its research and dissemination activities. NIE has recently named a new Director, Manuel Justiz, who has shown remarkable leadership in moving the Institute toward research excellence. We urge the committee to support funding for NIE of $55 million to enable it to continue its knowledge-building capacities in the path set out by Dr. Justiz.

National Institute of Handicapped Research (NIHR)

The National Institute of Handicapped Research (NIHR) was established to provide for a comprehensive and coordinated approach to the administration of research, demonstration, and related activities concerning the rehabilitation of handicapped persons, for healthy, productive lives. NIHR received $30 million for FY 83 and level funding is proposed for FY 84. An estimated 6-7% of the NIHR budget supports the training of individuals, including psychologists, who conduct rehabilitation research and provide rehabilitation services. The human and economic importance of rehabilitating the handicapped cannot be overestimated. We strongly recommend that NIHR pursue a more balanced research agenda, reflecting the total range of factors, including biobehavioral and psychosocial, related to successful rehabilitation.

Education of Handicapped Children

The Administration has proposed level-funding ($1.1 billion) for the 12 categorical programs that constitute the federal share in special education. A proposed gain of $28 million in P.L. 94-142 State Grants, however, would be offset with cuts in discretionary programs, especially deaf-blind centers, early childhood education, and special education personnel development. The proposed reductions in these and other discretionary programs for special education act to de-emphasize the critical federal role in stimulating new ideas in service delivery to deaf-blind children and to very young children with handicaps. Accordingly, we recommend that discretionary funds for special education be restored to their FY 83 levels.

Office of Human Development Services

The Office of Human Development Services administers many of the federal human services programs for the aged, children, youth and families, developmental disabilities and native Americans. Under the Reagan Administration, many research and demonstration programs have been consolidated or severely reduced. The most drastic decreases in funding are in the Human Resources Research and Demonstration programs (covering child abuse, child welfare and adoption) which are cut by nearly 60 percent; and the Administration on Aging Research Training and Discretionary Program which is cut by nearly 80% from $22.2 million in FY 83 to $5 million in FY 84. Critical information on the effectiveness of programs for our vulnerable and dependent population is being lost as a result. It is imperative that funding for these important programs be restored at least to FY 83 levels.

Family Planning Services

According to HHS, 4.2 million poor women and adolescents will receive family planning, counseling, and health education services in FY 83. In addition to providing needed health services, these programs yield a documented savings of $2 in public health and welfare costs for every $1 invested. For teenagers, the result is even more dramatic, where each dollar invested saves $3 in health care and welfare costs the very next year. Despite this phenomenal public health record, about two-thirds of all poor women and half of all teenagers at risk for unintended pregnancies are still not able to obtain family planning services from any source. Accordingly we urge full funding of Title X at the FY 84 authorization level of $155 million.

We are pleased to have been able to express our views.

Dr. JACKSON. Second, we urge the committee to fund the ADM block grant at $483 million, an increase of only $14 million over the fiscal year 1983 appropriations and the emergency jobs bill supplemental. This increase will help compensate ADM service programs for inflation that has occurred since 1981.

Finally, we urge the committee to emphasize NIMH's continuing responsibility to collect, analyze, and report on mental health statistics and to continue its important function as the sole source of national level information about needs, personnel, services, and new approaches.

Thank you, Senator Proxmire, for the opportunity to state our views.

[The statement follows:]

STATEMENT OF DR. JOHN H. JACKSON

I am Dr. John Jackson, a psychologist from Milwaukee, Wisconsin, and head of the Department of Psychological Services for the Milwaukee School System. I am here representing the 65,000 members of the American Psychological Associaton and the Association for the Advancement of Psychology. I am pleased to have the opportunity to testify before you today.

RESEARCH

Psychologists have several major concerns about appropriations for the National Institute of Mental Health. First is that funds continue to be available for vital research into the behavioral, social and biological aspects of mental disorders and their causes, assessement and treatment. We fully support the NIMH research budget proposal of $172 million.

Within this $172 million, however, psychologists and other social and behavioral scientists have continuing concerns about the severe Administration restrictions on the funding of social research. We believe these restrictions violate NIMH's Congressionally mandated mission calling for "the broadest possible participation . . . of medicine, science, the social sciences and related disciplines."

We want to emphasize that as social and economic conditions have worsened in many parts of America, so the number of our citizens with mental and emotional disabilities has increased. Research into the social, economic, and family co-determinants of mental and emotional dysfunction is absolutely vital -- not only to help practitioners treat people in need, but also to help policy makers assess the real personal effects of national decisions. Yet, basic research on such topics as "unemployment, indequate housing, divorce, and criminal behavior" is not allowed under current guidelines. This Committee has called upon ADAMHA in the past to report on the effect of NIMH's social research policy. To our knowledge, the report has not been delivered. We ask the Committee to renew its request.

RESEARCH TRAINING

Another concern is that funds continue to be available for research training. We fully support the aims of the NIMH research training program and urge a restoration of funds to the FY 81 level of $19.5 million. The research training budget has reduced to $15.4 million the past two years, and the result has been a drastic reduction in the number of students supported, from over 1350 students in FY 80 to a projected 880 students in FY 84. The core of the mental health research enterprise is in danger because of this decline. First year enrollments in some research-oriented fields of psychology are 30 percent lower than a few years ago. We caution that some areas of research may need a decade to rebuild if a critical mass of young scholars is lost now. We urge this Committee to help reverse this trend.

CLINICAL TRAINING

A major concern is clinical training of mental health professionals, and we would like to address three points:

1) Continuing the NIMH clinical training program;
2) Greater use of the "payback" requirement as a way to ensure services to underserved populations; and
3) The need for a Congressional requirement that funds be distributed more equitably among the four core mental health professions.

First, we ask for continuation of the NIMH clinical training program and restoration of funding to the FY 82 level of $42.2 million. NIMH has calculated that there is a need for 91,000 practitioners in each of the four core mental health disciplines -- psychology, psychiatry, clinical social work and mental health nursing. As of 1980, they count only 44,800 psychologists, 38,700 psychiatrists, 36,600 social workers, and 51,300 nurses.

Additionally, the need for trained personnel to treat underserved populations is well documented and often quite tragic. Consider the following facts:

- The National Coalition for Jail Reform reports that there are fewer than ten jails in the entire country that have any mental health personnel available to treat disturbed arrestees or prisoners. Further, 77 percent of the nation's jails have no health care facilities at all.
- According to the report of mental health experts associated with the 1981 White House Conference on Aging, one-half to three-quarters of nursing home residents suffer from significant degrees of mental impairment. However, according to this group, "only a very small fraction of all patients living in nursing homes have access to treatment by a mental health professional."

. The nation's elderly constitute 11 percent of the population, or 25 million persons. This number is expected to double in 50 years. NIMH estimates that in 1977 there were only 100 clinical psychologists with qualifications and expertise to work with the elderly, and only 50 mental health nurses.

. According to the Children's Defense Fund, "of the three million seriously (mentally) disturbed children in this country, two thirds are not getting the services they need. Countless others get inappropriate care." These same findings were reflected in the report of the 1978 President's Commission on Mental Health, with their additional finding that there is a shortage of specialists trained to work with children and adolescents. According to the Director of NIMH's training division, there are only 5000 clinical child psychologists practicing in the United States, and this number is "woefully inadequate."

. According to NIMH, "There are...an insufficient number of psychologists in rural areas, especially those who have been prepared to understand and meet the particular mental health needs of rural populations." Although there are 54 million people in rural America, there are at present only 4 psychology training program offering substantial training in rural mental health. In most states with large rural areas, the only mental health professionals are located in the few major cities -- other areas are virtually without available care. According to a 1979 survey, primarily rural areas have 4.2 mental health professionals per 100,000 population, while primarily urban areas have 6.3 per 100,000 and some areas have 10.1 practitioners per 100,000 population.

. The needs of minorities for relevant mental health services is widely acknowledged -- and this Committee has supported the NIMH Minority Fellowship Programs strongly in the past. Although there are 46 million minority citizens in the country, there are only 830 minority licensed psychologists. Clearly, 20 percent of the U.S. population cannot be served by 2.6 percent of U.S. psychologists. Your continued support for clinical training of minorities is most important.

. NIMH also reports that "advances in the treatment of the chronically mentally ill have increased the need for psychologists trained to work in inpatient facilities and in community settings for deinstitutionalized patients."

Because of these needs in each of these service areas, our second point is that we urge this Committee to require that NIMH use its clinical training funds so as to maximize the supply of fully-trained mental health professionals who are skilled in the understanding and delivery of services to unserved and underserved populations. Specifically, we urge you to require that no more than 25 percent of the clinical training funds be used to support trainees who will not have a "payback" obligation to deliver mental health services to these populations. The requirement of a "payback" in the form of service delivery is authorized by Section 303(d)(1) of the Public Health Service Act. By requiring that 75 percent of NIMH's clinical training funds be used to support students who will later be obligated to deliver services to shortage populations, you will have made possible a vital human professional resource to treat the needs of those citizens who are most in need.

Our third point is that we urge you to require that NIMH fund each of the mental health disciplines, in an equitable balance, so as to produce the best possible range of practitioners and approaches available to deliver services. The allocations for clinical training funds set forth by NIMH for FY 83 ignore the express language of both the House and Senate Committees for a reasonable and equitable balance in the distribution of clinical training funds among the four core professions. Psychiatry received a disproportionate share of the funds allocated, $3.773 million -- compared to $1.9 million for nursing, $1.1 million for psychology and $1.1 million for social work.

BLOCK GRANT

The Alcohol, Drug Abuse and Mental Health Block Grant currently provides minimal funding for service programs across the United States. Although health care costs rose 13 percent in 1982, and by 12.5 percent in 1981, funding for the A-D-M Block Grant has increased by only 3 percent over that time. This has produced such a critical shortfall of funds, that $30 million was added to the Block Grant by the emergency jobs bill -- as the states were totally unable to meet the pressing mental health needs of millions of unemployed citizens.

We urge this Committee to fund the A-D-M Block Grant at $483 million, an increase of only $14 million over the FY 83 appropriation and the jobs bill supplement. This small increase would allow some progress in compensating A-D-M service programs for the loss in constant dollars suffered since 1981, and it would help to preclude the necessity for future emergency supplemental appropriations.

The Administration proposes combining the A-D-M block grant with Preventive Health and Child and Maternal Health block grants and to allow a shifting of up to 20% of the funds within the triple block. We urge the Committee to help maintain the A-D-M grant as a separate block and to help continue the initial restriction that 95% of the funds must be distributed within the major program areas.

DATA COLLECTION

A final concern is that NIMH needs to have its role in the collection and analysis of mental health-related data clarified by the Congress. When the Alcohol, Drug Abuse, and Mental Health Block Grant was created, NIMH's ability for work in epidemiology was severely curtailed. We urge this Committee to emphasize the Institute's continuing responsibility to collect, analyze and report on mental health statistics -- and to continue its important function as the sole source of national-level information about needs assessment, personnel, services, and new approaches.

I thank you for this opportunity to give our views.

Senator PROXMIRE. Thank you, Dr. Jackson.

Dr. Jackson, will you introduce the gentleman who is with you?

Dr. JACKSON. I am sorry. This is Mr. Clarence Martin, executive director of the Association for the Advancement of Psychology.

Senator PROXMIRE. Very good.

Senator PROXMIRE. And where are you from, sir?

Mr. MARTIN. I have been here a long time. I am from New Orleans originally, sir.

Senator PROXMIRE. I was hoping you were from Wisconsin. As soon as you spoke, though, I knew you were from a little south of our State. [Laughter.]

But happy to have you with us.

Dr. JACKSON. He has visited Wisconsin. [Laughter.]

Senator PROXMIRE. He has done what?

Dr. JACKSON. He has visited Wisconsin. He escaped too, Senator.

Senator PROXMIRE. Well, some people say that I am just a visitor in Wisconsin. I was born in Illinois. So I am a carpetbagger. [Laughter.]

May I ask you, Dr. Jackson—on page 3, you say, "The National Coalition for Jail Reform reports there are fewer than 10 jails in the entire country that have any mental health personnel available to treat disturbed arrestees or prisoners."

Dr. JACKSON. Yes.

Senator PROXMIRE. Are there any estimates that you have of the percentage of incarcerated prisoners who suffer from mental illness?

Dr. JACKSON. Mr. Martin will respond, sir.

Mr. MARTIN. If I may, Senator.

We have no estimates because no studies have ever been undertaken.

Senator PROXMIRE. Any proposal for studies? It seems to me this would be quite interesting if we could do something constructively.

Mr. MARTIN. The National Coalition for Jail Reform and the Mental Health Liaison Group—of which, as it turns out, I am the chairman of the subcommittee for mental health in the jails—have been studying various possibilities. We have no proposal for funding such a proposition at the present time, but we are looking for some way to do it on a State-by-State basis at this time.

Senator PROXMIRE. Staff tells me the American Bar Association is doing some work in this area.

Mr. MARTIN. I think the question that the American Bar Association is addressing and the one we are addressing are a little bit different. I think their focus is primarily on the question of dangerousness of prisoners from the point of view of mental and emotional problems.

Senator PROXMIRE. That would certainly be one element.

Mr. MARTIN. It certainly is, yes.

Senator PROXMIRE. But I would agree with your thrust here, that undoubtedly this is an area where we could constructively assist people to have effective rehabilitation.

I am sure that this is a cause of a great deal of crime.

Mr. MARTIN. Well, there are some serious issues here, not only in terms of these people going untreated, but their impact upon themselves, and also the impact upon the other inmates, because if you have disturbed people packed into a prison, the effect they have on the other inmates is substantial in itself.

Senator PROXMIRE. Of course, when they get out of prison, if they simply serve that time to get out——

Mr. MARTIN. That is right.

Senator PROXMIRE [continuing]. And continue to have a terrible mental illness which causes violence, then there is a real problem.

I noticed on the television last night there was a report of a person who was mentally ill who was missing from this area and a great fear that he might revert to violence without the medicine he had, and so forth.

I think there is too little recognition of this aspect of criminality.

Well, gentlemen, I thank you very, very much. Dr. Jackson, an excellent statement. We deeply appreciate it, and I hope you have a good trip back to Milwaukee.

Dr. JACKSON. Thank you, Senator. I appreciate it.

Senator PROXMIRE. Very good.

STATEMENT OF BORIS ASTRACHAN, M.D., PROFESSOR OF PSYCHIATRY, YALE UNIVERSITY SCHOOL OF MEDICINE, CONNECTICUT, ON BEHALF OF THE AMERICAN PSYCHIATRIC ASSOCIATION

Senator PROXMIRE. Our next witness is Dr. Boris Astrachan, who is a professor of psychiatry, Yale University School of Medicine, Connecticut, representing the American Psychiatric Association.

Did I pronounce your name correctly, sir?

Dr. ASTRACHAN. You certainly did.

Senator PROXMIRE. Well, thank you, I appreciate that.

Dr. ASTRACHAN. Thank you.

Mr. Chairman, I am a practicing clinician and administrator, a teacher, and I want to make clear that my first priority and that of the groups for whom I speak is the support of research, for we have only just begun to comprehend something about the existence of the mind within the brain.

For the first time we have hope for increasingly sophisticated treatment, for the development of new and impressive diagnostic tools, and eventually even prevention, and yet inadequate growth into research into the causes and the improved treatment of mental illness, alcoholism, and drug abuse. Inadequate growth of funding for clinical and research manpower training and in-service delivery programs serves to reinforce the public's fear, stigmatization, and misunderstanding of the devastating illnesses which we treat.

The magnitude of the problem is enormous, as you have already heard. Literally billions of dollars are expended, and the cost to the Nation for schizophrenia, Alzheimer's disease, effective disease, and billions more for others— ADAMHA estimates that overall the cost is $106 billion.

The economic costs, the costs in terms of human suffering, social dependence, and lost productivity are staggering. In light of the problem, as was mentioned earlier, research support is remarkably limited, and as research is getting more and more sophisticated, support is harder to get.

Let me tell you about it briefly in practical terms from my own perspective.

At our center, the Connecticut Mental Health Center, we have a superb research facility, a superb research group, but since priorities for grant funds have become increasingly low—now down to 163 in psychiatry—grants are harder to get.

One of our best scientists, a man whose work is crucial to the work of six others, recently received a priority score which just missed funding within 10 points. If his work is seriously curtailed, the work of six other fully funded researchers is threatened. In this case we will be able to compensate, and we can compensate for a year. We soon won't be able to compensate if the process does not improve.

In light of the magnitude of these clinical problems, the unprecedented scientific opportunities for research, I urge your favorable consideration of $216 million for ADAMHA's extramural research programs in fiscal year 1984.

Mr. Chairman, to a very great extent, psychiatric training occurs in settings in which service and training are remarkably underfunded and undervalued. Regrettably, the administration's budget seeks to eliminate funds for clinical training in fiscal year 1983.

This committee and the Congress dealt with the same recommendation with clear understanding. We hope you will do so again.

I want to briefly say something again about what clinical training moneys mean in our program at Yale. In the department of psychiatry, clinical training moneys do not directly support stipends. The payback issue is a different one because the Congress and NIMH have seen fit to make stipend support of only limited importance in psychiatric training.

It supports the freeing up of time of practitioners so that they teach, and most of the money going into psychiatric training frees up my time, the time of other people from directly earning dollars so that we can teach, because there is very limited fiscal support for teaching.

I finally want to make a brief comment about an area where the APA has never made comment; that is, the Federal support for St. Elizabeths Hospital. Here the administration's proposals for fiscal year 1984 are potentially so damaging to the effective operation of that hospital and to the quality of service it provides to the citizens of the District of Columbia that we felt that we need to speak out for those patients who will be poorly served if the 20-percent reduction in the hospital's personnel budget ceiling is put into effect. We believe such proposals are appalling and potentially injurious to the citizenry of this district.

Thank you, sir.

Senator PROXMIRE. Well, thank you very, very much for a fine statement, Dr. Astrachan. I very much appreciate it and just wish we had more time for exploring this. We could take several hours, I am sure, productively.

Thank you, sir.

Dr. ASTRACHAN. Thank you.

[The statement follows:]

STATEMENTS OF BORIS ASTRACHAN, M.D.

I am Dr. Boris Astrachan, Professor of Psychiatry at the Yale University School of Medicine and Director of the Connecticut Mental Health Center in New Haven. I am pleased to appear before the Subcommittee not only to represent the particular concerns of the American Psychiatric Association regarding the President's proposed FY 1984 appropriations for the Alcohol, Drug Abuse, and Mental Health Administration, but also those of the American Association of Chairmen of Departments of Psychiatry (a national association representing over 125 academic departments of psychiatry in the nation's medical schools), the American Association of Directors of Psychiatric Residency Training (an organization representing over 90% of the more than 200 psychiatric residency training programs in the nation), and the American Society for Adolescent Psychiatry (a national organization of 1700 psychiatrists who specialize in treating mentally ill adolescents).

I shall restrict this first statement to the research and research training programs of the Alcohol, Drug Abuse, and Mental Health Administration.

Mr. Chairman, we know that you and members of this Subcommittee are aware of the range, seriousness, and staggering economic costs of the problems that ADAMHA addresses through its national programs. Inadequate growth in research into the causes and improved treatment of mental illness, alcoholism, and drug abuse, in the funding of ADAMHA clinical and research manpower training, and in service delivery programs serve to reinforce the public's fear, stigmatization, and misunderstanding of these devastating illnesses.

There are three important elements with respect to health research to be considered in your deliberations:

1) the magnitude of the problem in our society, i.e., the number of Americans affected, the degree of incapacity and suffering that results, and the economic impact in terms of both cost of care and lost productivity;

2) the difficulty of the problem from the standpoint of its medical and scientific complexity and the limitations in presently available knowledge as to causes, pathology, prevention, diagnosis, course, treatment, and outcome; and,

3) realistic prospects that enhanced research support will be scientifically and clinically productive for the identified health problem area; these prospects, in turn, rest on the recent track record of relevant research advances, the richness of the field in promising research leads, the availability of appropriately sophisticated research technology and methods, and an adequate body of well-qualified researchers.

With respect to each of these three critical considerations, significantly increased support for research in mental illness and alcohol and drug abuse is objectively and thoroughly warranted.

As to the magnitude of the problem, in any one year 15-18% of the American population suffers from a mental disorder involving a degree of incapacity that interferes with employment, attendance at school, or independent living; some 12 million children under age 18 suffer from serious mental disorders; 25% of elderly persons "written off" as senile are in fact suffering from unrecognized but treatable mental disorders; 4 million Americans are at risk for schizophrenia -- one of the most devastating and often chronic forms of mental illness; major affective disorders (depression and manic-depressive illness) afflict 8-14 million Americans each year and involve all age groups; some 10 million American adults are alcoholics or problem drinkers, and about 3 million children 13-17 have significant alcohol-related problems; approximately 2400 babies born in the U.S. each year suffer from Fetal Alcohol Syndrome, a profound physical and mental disorder associated with maternal drinking during pregnancy, and an additional 36,000 pregnancies annually are adversely affected by alcohol to a degree less severe than the full-blown FAS; it is estimated that currently 28 million Americans abuse illegal drugs, ranging from heroin, cocaine, and marihuana to sedatives, stimulants, tranquilizers, and hallucinogens -- an abuse that often leads to the undermining of personal and social responsibility and productivity and which can culminate in literal self-destruction.

The ADAMHA estimates that in 1977 health problems of mental illness and alcohol and drug abuse cost our nation a dismaying $106 billion. Unfortunately, it is predictable that the cost in 1983 will be even higher.

Mr. Chairman, regarding the magnitude of the problem, there can be no doubt that mental illness and alcohol and drug abuse are widespread problems of grave consequence in American society, whether viewed simply in terms of economic cost or in terms of human suffering, social dependence, and lost productivity.

Concerning the difficulty of the problem, only within recent years have greatly improved research methods and the availability of sophisticated electronic technology combined to open the door to a new era of productive scientific inquiry into the brain's subtle and manifold functions and their linkages to normal and pathological behavior. Indeed, a majority of the most promising areas of brain research today arise from basic new knowledge and technological breakthroughs gained only in the last few years.

In the area of clinical, behavioral, and epidemiological research, new and much more sophisticated experimental designs and methods have been required. These new designs and methods have necessitated progressively more objective and quantified measures of behavior and subjective states. While perhaps not so dramatic as methodological advances in the basic brain sciences, these developments have presented -- and continue to present -- a comparable order of scientific challenge for the clinical researcher and the behavioral scientist.

By no means do I intend to imply that the scientific and clinical difficulties of the problem have been resolved, but an impressive beginning is underway. Progress in recent years has been unprecedented, has already yielded significant human and economic benefits, and is the best available predictor of likely future benefits if the effort is sustained and enhanced.

I should like now to turn to an overview of just a few of the most promising recent research developments affecting mental illness and alcohol and drug abuse. Taken collectively -- and in the larger context of the many more examples there is not time to mention -- they form an extraordinary track record of accomplishment on a broad range of scientific fronts, and justify the confidence that future enhanced research support will be scientifically and clinically productive.

-- Positron emission tomography (PET) permits direct and non-invasive visualization of chemical and physiological events within the intact brain. PET is being applied productively to the study of such serious mental disorders as schizophrenia. For example, schizophrenic patients show diminished utilization of glucose (hence reduced brain activity) in portions of the frontal cortex and in the region of caudate nucleus. PET technology also now makes possible the differentiation (heretofore very difficult) between certain forms of schizophrenia and the manic phase of manic-depressive illness -- a distinction highly important for prognosis and effective treatment.

-- Recent computer technology and computer enhancement techniques are being applied to mapping the complex patterns of electrical activity of the brain, a procedure requiring highly sophisticated equipment and which can be carried out in conjunction with PET. Already the combined methods have shown a coincidence of abnormal electrical activity in the same brain areas where PET scans indicate diminished neurochemical activity.

-- In a quite different area, researchers supported by the NIMH continue to explore new techniques for transplanting neural tissue for repair of malfunctioning or damaged areas of the brain. This work, still in its experimental stages in animals, is advancing with steady promise, and potentially has far-reaching implications for the msot serious forms of mental disorder.

-- The development and clinical introduction of lithium carbonate for the treatment of manic-depressive illness is, in terms of ameliorating human suffering and simultaneously reducing health care costs, one of the most striking events in psychiatry during the past decade. Lithium carbonate, a simple chemical salt, is regularly effective in restoring the grossly disturbed manic patient to normal within a few weeks. During the past decade this new therapy has helped millions of Americans, and at the same time is estimated to have resulted in savings in cost of treatment (compared to former less effective treatments) of over $4 billion. Mr. Chairman, these savings are more than all the funds ever appropriated by Congress for research on mental illness!

-- Recent research increasingly supports the view that the rate at which different persons metabolize alcohol has an inheritable genetic basis. An enzyme, alcohol dehydrogenase, is largely responsible for the metabolism of alcohol in the body. It is now known that this enzyme can occur in different molecular forms -- apparently genetically determined -- and that these forms may vary with respect to alcohol metabolism. This significant research finding may well lead the way to an improved understanding of the common observation that different individuals and different ethnic groups vary widely in their susceptibility to alcohol and its effects. There are also important implications for prevention.

-- Data published during the past year indicate that certain patterns of electrical function of the brain can differentiate alcohol users at high risk of developing alcoholism from those at low risk. This direct electrophysiological measure, among other implications, has special significance for research on prevention.

-- With regard to the damaging effects on the fetus of maternal drinking, especially early in pregnancy, there is now some encouraging evidence that these effects may be at least partially reversible in utero. This is clearly an important research lead that should be pursued.

-- NIDA-supported research (along with that of NIMH) contributed substantially to the discovery of opiate receptors in the brain and, subsequently, of the endorphins and enkephalins (endogenous opioids in the body). New evidence now suggests the possibility of specific brain receptors for tetrahydrocannabinol, an active ingredient of marihuana. Effective treatment and prevention of drug abuse must rest ultimately on a precise understanding of the sites of action and the physiological mechanisms by which drugs exert their effects on the brain, and thereby on subjective states and on behavior, including the phenomena of tolerance and dependence. The discovery of opiate receptors and endogenous opioids has been a landmark development in moving toward this understanding.

The quality of the ADAMHA research program commands high respect throughout the scientific community. Further attesting to this quality is the fact that ADAMHA-supported researchers were recent recipients of a Nobel Prize, the Lasker Award, and the McAlpin Research Achievement Award, among others. A growing interest on the part of the general public in research on mental illness and alcohol and drug abuse should also be noted. This is a change from the past, and is reflected by the extensive coverage given new developments by newspapers, national news magazines, and other media during the past year.

The research advances I have described do not come about quickly or independently of a broad base of scientific effort. As the Committee knows: such advances are brought about only by long and sustained continuity of research funding support and effort ranging from the step-by-step accretion of new basic science knowledge, to its integration into the existing base of knowledge, and then to the measured extension of that knowledge into the realm of carefully evaluated clinical application. Indeed, this process of sustained continuity of effort is essential for progress in the natural and clinical sciences. Today, the research enterprise in the biomedical and behavioral sciences, including those specifically relevant to ADAMHA, requires as never before the painstaking assembly of complex laboratories and the bringing together of highly qualified teams of basic and clinical researchers representing a wide range of scientific disciplines and expertise. These arrangements often take years to build.

We are pleased that for FY 1984 the Administration, by proposing budget increases, recognizes the national importance, quality, and scientific opportunity reflected in the ADAMHA research programs. Nevertheless, in our judgement the proposed levels for FY 1984 (particularly for NIMH) still fall short of what is needed to repair the damage inflicted by previous destructive budget cuts. In light of the magnitude of national problems of mental illness and alcohol and drug abuse -- and the unprecedented scientific opportunities for productive research now present -- I urge your favorable consideration of $216 million for ADAMHA extramural research in FY 1984; more specifically $130 million for NIMH, $35.5 million for NIAAA, and $50.5 million for NIDA.

Mr. Chairman, well-trained basic scientists and clinical investigators are the essential instruments of research progress. Because of the years of training required (5 to 8 graduate and postgraduate years), there is necessarily a long lead-time in producing highly qualified researchers. If the present extraordinary research promise in mental illness and in alcohol and drug abuse is to be realized in the coming decades, it is time now to assure the future availability of the well-trained men and women upon whom the nation must depend for the success of that effort. Yet, during the last 15 years there has been a more than 50% reduction in the number of research trainees supported by ADAMHA (down from nearly 2600 to 1000), largely as a consequence of a steady decline in budget (in constant dollars).

In terms of increased future needs now clearly evident, the following are particularly critical for ADAMHA: 1) clinical researchers, i.e., fully qualified clinicians with additional sound state-of-the-art training in research methods for patient-oriented investigations and application of burgeoning basic science knowledge to specific clinical problems; 2) epidemiologists and prevention-related researchers to take advantage of new methods and rapidly expanding research opportunities in these promising fields; and 3) biological and biobehavioral scientists necessary to maintain in coming years the present highly productive research effort in basic brain and behavioral sciences.

The approximately 2600 research trainees ADAMHA supported 15 years ago are responsible for much of the research manpower available today (and recent research progress). The President's FY 1984 proposal would allow ADAMHA no increase in research trainees over the 1000 in FY 1983. To safeguard the future national capacity for quality research in mental illness and in alcohol and drug abuse, ADAMHA needs the resources in FY 1984 to support the training of at least 1400 scientists (1200 by NIMH, and 100 each by NIAAA and NIDA). This realistic goal would require an overall ADAMHA research training appropriation of $24,701,000 ($21,173,000 for NIMH and $1,764,000 each for NIAAA and NIDA).

Thank you for allowing me the opportunity to testify and I look forward to working with this Committee in developing sound funding levels for these programs.

I am Dr. Boris Astrachan, Professor of Psychiatry at the Yale University School of Medicine and Director of the Connecticut Mental Health Center in New Haven. I am pleased to appear before the Subcommittee not only to represent the particular concerns of the American Psychiatric Association regarding the President's proposed FY 1984 appropriations for the Alcohol, Drug Abuse, and Mental Health Administration, but also those of the American Association of Chairmen of Departments of Psychiatry (a national association representing over 125 academic departments of psychiatry in the nation's medical schools), the American Association of Directors of Psychiatric Residency Training (an organization representing over 90% of the more than 200 psychiatric residency training programs in the nation), and the American Society for Adolescent Psychiatry (a national organization of 1700 psychiatrists who specialize in treating mentally ill adolescents).

I shall restrict this second statement to the clinical training program of the National Institute of Mental Health, the Alcohol, Drug Abuse and Mental Health Block Grant, the NIMH Community Support Program, the Guaranteed Student Loan Program, and Saint Elizabeths Hospital.

First, NIMH clinical training: The Administration's FY 1984 proposal for this program is, regrettably, a budget line of zero! This is the same proposal that was made for FY 1983, and now, as then, directly contradicts your Committee's leadership and concern as to the need for continuing this program. In FY 1983 this Committee and the Congress met the challenge prudently and with great understanding of the complex issues involved. After weighing the evidence presented, you set forth clear Congressional priorities and directed the establishment of a new NIMH clinical training program addressed to those priorities, and the Congress provided an initial appropriation of $21.5 million for support of this activity in FY 1983.

Mr. Chairman, all of us in the mental health field with an abiding concern for the availability and quality of professional care for all mentally ill Americans recognize that the NIMH clinical training program has been -- and, thanks to your efforts, continues to be -- the key to attaining that goal. Hence, your decisive action last year was most heartening.

Today, I shall not repeat the data and arguments contained in previous APA testimony, though they still are germane, for it is clear that they have been heard and have been given close and thoughtful consideration by the Congress through this

Committee's leadership. There are, however, two issues on which I feel it would be helpful to comment.

The first concerns the long-standing effort to interest more young psychiatrists in careers in the public service sector. Many public sector positions for psychiatrists have gone unfilled -- especially in mental hospitals -- because they have been both professionally and economically unattractive. Recently, at NIMH initiative, a growing number of academic training centers have begun working more closely with state and other public service facilities, often through formal affiliation arrangements. These efforts now appear to be paying off. An especially striking example -- and perhaps a model for other training centers -- is taking place in the State of Maryland. I should like to quote the conclusion drawn by the authors in a recent publication in the journal Hospital and Community Psychiatry:

> "From July of 1976 through December 1981, 67 psychiatrists who graduated primarily from American medical schools and who had completed university residency training programs were recruited into Maryland's state mental health system. As of 1981, 43 of these psychiatrists still worked in inpatient facilities; they represented 33% of all state hospital psychiatrists in Maryland. The Maryland Mental Hygiene Administration and the University of Maryland have used general strategies to develop psychiatric manpower and to improve employment conditions. They established close linkages between academia and the public sector and demonstrated positive, effective leadership by psychiatrists within the state mental health system."

Mr. Chairman, I should be pleased to discuss with you and other members of the Committee the full report on the Maryland experience.

The second issue I wish to address concerns the particular nature of the support required in the medical education community for accomplishment of the clinical training objectives the Congress has established. Psychiatry and psychiatric training, including improved instruction of medical students and primary care residents, derive their academic tradition and professional characteristics from the larger field of medicine (of which they are an integral part). Graduate physician trainees, in the course of their specialty professional education, work in hospitals and other clinical settings; it is essential for much of their training that they provide supervised direct clinical services as house officers, in return for which they are provided a modest stipend. In this context, the most urgent need of psychiatric education centers is funds to supplement teaching costs, i.e., to free up faculty from other income-producing duties so that they may concentrate more time in direct teaching and supervision in priority subject matter areas. There is no health insurance or similar reimbursement for teaching, and time spent in this activity is time not spent by senior clinical staff in other reimbursement-producing functions. Thus, assistance in helping to defray teaching costs (rather, say, than student stipends) is critical for the field of psychiatry in assuming its responsibilities in connection with the clinical training program mandated by this Committee and the Congress last year.

The NIMH has moved vigorously -- and, while it would be more politic to say inadequately on behalf of psychiatry, I believe on the whole very effectively -- to implement the Congressional mandate of equitable funding among the disciplines. In all areas, particular attention is being paid to providing opportunities for minority students, a major vehicle for which is the Minority Fellowship Program supported in each of the four core disciplines.

As you know, clinical training requires 3 to 5 years at the graduate and post-graduate levels to produce a qualified specialist in the mental health professional disciplines. Thus, most of the awards made under the new program in FY 1983 will need continuation support in FY 1984. In addition, Mr. Chairman, in view of the still-relevant and pressing shortages described in APA testimony before this Committee in 1981 and 1982, and the large number of high quality new and competing applications now on hand or expected for FY 1984, I believe an increase in funding for this new progrom is clearly justified. An increase would be professionally and educationally sound as the program enters its second year. Accordingly, I respectfully recommend an FY 1984 NIMH clinical training budget of $25 million. This would allow continued funding of projects initiated in FY 1983 and a modest number of new and competing awards of the highest priority in FY 1984.

Next, the Alcohol, Drug Abuse, and Mental Health Block Grant: We want you and this Committee to know how much we appreciate the recent much-needed action by the Congress in including an additional $30 million for this Block Grant in legislation this past March for "Emergency Expenditures to Meet National Needs." I can certainly confirm your understanding that conditions of high unemployment and economic dislocation, especially when protracted, are associated with an increase in the occurrence of mental disorder (particularly depression) and alcohol and drug abuse. These additional funds, if promptly and effectively deployed by the states, will do much to reduce the suffering and potential future loss of productivity that would otherwise result from these conditions.

Nevertheless, we continue to have serious concern as to the long-term level of Federal funding for the Alcoholism, Drug Abuse, and Mental Health Block Grant, and, consequently the capacity of states to meet the needs of the substantial numbers of citizens who remain unserved and underserved. For FY 1984 the Administration proposes an increase of less than 2% over the 1983 level (before the $30 million just added by the Congress). This amount is insufficient to reverse the recent trend of reduction in outpatient mental health services for the chronically mentally ill, in services for alcohol and drug abusers, in community consultation and education programs, and in programs aimed at prevention. During the past two years we have seen a decline in professional staff of Community Mental Health Centers, and these facilities are becoming more and more dependent on self-paying or private insurance patients for service fees simply to continue operating at all. An appropriation of $469 million in FY 1984 would help significantly to address the most urgent needs; I respectfully ask that you give this level your favorable consideration.

In a related matter, Mr. Chairman, this year -- as in FY 1983 -- the President proposes to terminate all Federal support for the NIMH Community Support Program (CSP). This is a national demonstration initiative begun in 1977 which is designed to assist states and communities to improve opportunities and services for chronically mentally ill adults being diverted or discharged from inpatient facilities in an era of "deinstitutionalization." Over half of the chronically mentally ill now reside in the community; altogether too many of these do not have available to them the network of social and medical services they require to meet their minimal needs. CSP projects are gradually succeeding in establishing the chronically mentally ill as a priority population. In the pilot states, significant state and local resources have been mobilized for community services for CMI individuals and innovative and model programs have been developed. Evaluation of local CSP demonstration projects indicate that these programs are reducing hospital use by as much as 50% -- from an average of 65 to 32 days per year after one year in the improved system. These efforts are clearly cost-effective.

Last year the Congress determined that the CSP demonstration program should continue, and appropriated $6 million for this purpose in FY 1983. The APA strongly endorsed your action last year, and respectfully urges that you continue the program again in FY 1984 at no less than the $6 million level.

Mr. Chairman, the organizations I represent are very much concerned about the Administration's FY 1984 proposals for the Guaranteed Student Loan Program (GSL). As you recall, last year we commended the Committee for its decisiveness in rejecting the Administration's proposal to phase out graduate student eligibility under this program. We believed, with you, that this proposal would eliminate an important source of support for medical students and psychiatric residents and force these groups to seek a specialty choice with higher income potential. We are pleased that this proposal has not been reintroduced, yet are dismayed by a new proposal which increases the GSL origination fee from 5% to 10% for graduate and professional students. If adopted, this change would go into effect on July 1, 1983. GSLs currently go to roughly 525,000 graduate and professional students who borrow up to $1.8 billion to finance advanced studies. Origination fees charge the borrower in advance for interest due on a loan. Such fees reduce Federal outlays on special allowances and in-school interest payments normally paid quarterly to lending agencies. This proposal makes financing graduate education more difficult, makes short-term savings at the expense of overall objectives of the loan program, and singles out graduate and professional students for more difficult financial conditions. The potential effect would serve to reverse two decades of Federal policies and would affect not only financing questions but broader social policy questions such as: the effect on minority enrollment, the effect on graduate academic quality, and the choice of postgraduate careers and overall access to study for citizens from low-income backgrounds. The organizations I represent believe these Administration proposals are clearly not in the broad national interest, and therefore we strongly oppose them.

While the APA has rarely presented testimony concerning Federal budget proposals for Saint Elizabeths Hospital, the Administration's proposals for FY 1984 are, in our judgment, potentially so damaging to the effective operation of the Hospital and the quality of service it provides, that we must speak out.

Saint Elizabeths has a long and distinguished tradition of service to the mentally ill of the District of Columbia and eligible Federal beneficiaries. In addition, over many years it has provided sound training for thousands of mental health professionals in a wide range of disciplines. The Hospital is overwhelmingly the major local resource for inpatient psychiatric care, including hospitalization of emergency patients, committed patients, and forensic patients -- all categories requiring a high level of professional treatment. There is no indication that in FY 1984 the service demands on the Hospital will decrease, either because of reduced numbers of persons in the community needing care or because of expanded services to be provided by other sources.

The President proposes essentially an effective 20% reduction in the Hospital personnel ceiling in FY 1984, along with inclusion in this permanent ceiling of trainees and patient hires. These proposals, if accepted by the Congress, will very likely require a disrupting reduction-in-force, jeopardize the Hospital's JCAH accreditation and eligibility for Medicare reimbursement, seriously impair the quantity and quality of needed services now being provided the seriously mentally ill of the District of Columbia, and greatly handicap the operation of training programs.

Accordingly, Mr. Chairman, we strongly recommend the following: 1) that the FY 1984 permanent ceiling for Saint Elizabeths Hospital remain at the FY 1983 level; 2) that trainees and patient hires remain outside the computation of full-time-equivalent positions; and 3) that in FY 1984 the Hospital receive an indefinite Federal appropriation as in past years.

CONCLUSION

Mr. Chairman, I urge you and your colleagues on the Committee to offer an amendment to the proposed ADAMHA budget for FY 1984 which charts an appropriate course between the need for fiscal restraint and the need for adequate mental health, drug abuse, and alcoholism research, training, and services, and which provides the increases necessary to make available the needed knowledge, manpower, and services.

To this end, we respectfully request your consideration of our proposed appropriations levels in FY 1984. We should be pleased to meet with you to discuss them further.

STATEMENT OF HARLEY M. DIRKS, WASHINGTON REPRESENTATIVE, AMERICAN MENTAL HEALTH COUNSELORS ASSOCIATION

Senator PROXMIRE. Our next witness is an old friend of the committee and of this Senator. I am delighted to have Harley Dirks, the Washington representative of the American Mental Health Counselors Association.

Mr. DIRKS. Thank you, Mr. Chairman.

Senator PROXMIRE. Happy to have you here, Harley.

Weren't you the staff director of this subcommittee?

Mr. DIRKS. Yes, sir.

Senator PROXMIRE. For a few years?

Mr. DIRKS. Twelve years.

Senator PROXMIRE. For 12 years, heaven's sake. Well, you should be on the other side asking the questions.

Mr. DIRKS. Well, it is kind of nice to be the seller instead of the buyer once in a while. [Laughter.]

Senator PROXMIRE. Thank you. I am sure you are a good salesman. Go ahead.

Mr. DIRKS. The American Mental Health Counselors have some concerns about the proposed budget, Mr. Chairman, and the current fiscal policy.

As you are well aware, these are stressful times in America. Never in recent history have Americans witnessed such high unemployment, runaway deficits, unbalanced budgets, and cutbacks that acutely affect the poor, the sick, and the mentally unstable.

Everyone is trying to adjust to these challenges. Some are, yet many are not. In times such as these there is far greater incidence of mental stress and disorders. The rate of suicide and substance abuse continues to escalate.

To deal with these results of a worsening pattern, a supportive effort is required and skilled, well-trained professionals are needed. I think it is very clear that now is the time to reverse the landslide reductions in mental health programs and begin an effort to provide necessary means for effectively managing these problems.

Although we support the research initiatives proposed in the President's budget, we are disappointed to see only a small increase in research training and the proposed elimination of clinical training for mental health.

In fiscal year 1984, we seek restoration of the 1983 figure of $21.5 million for clinical training and an increase of $2.3 million for research training, so training can be funded at $36.9 million. Even this increase will not adequately restore funding levels of just a few years ago.

In the President's budget, training dollars for drug abuse and alcoholism are drastically underfunded. These funds for research training should be restored at least to levels that adequately reflect a maintenance of the program.

The American Mental Health Counselors Association is not totally dissatisfied with the general concept of the ADAMHA block grant. Yet funding for this program remains a meritorious concern.

Recently, Congress appropriated an additional $30 million in fiscal year 1983 for the ADAMHA block grant in the Jobs bill. This brought the 1983 appropriation figure to $469 million. We support adding this $30 million to the fiscal year 1984 baseline estimate of $439 million and request a fiscal year 1984 appropriation of at least $469 million.

Discretionary programs are the foundation upon which our basic health service delivery, education, prevention, research, and training systems are built. In the absence of Federal support, neither State nor local governments nor the private sector are financially capable of continuing these vital programs.

Health programs and administrators are still reeling from the impact of the billions of dollars in cuts they suffered in fiscal year 1982 and the millions lopped off in fiscal year 1983.

Now, before the full force of these cuts have been felt or examined, the administration proposes to reduce by millions more the amounts necessary to carry out discretionary health programs in fiscal year 1984.

The American Mental Health Counselors Association is aware of the current distressing economic climate. However, we are also aware that discretionary health programs are the most cost effective of our efforts, by reducing the need for greater future outlays in medical care.

It is very well known that the current economic outlook weighs heavily on the minds of many. Now is not the time to eliminate opportunities before us in health. Now is the time to accelerate our efforts to meet the challenges we face in coming years.

It is our belief that there should be no further reductions in the realm of discretionary programs. These programs have been the source of public health innovation and progress and have dealt with problems beyond the reach or authority of entitlement programs.

Congress has expressed a concern on the eligibility of disability recipients, but it appears that a chaotic review by the administration has led to serious financial setbacks and abrupt benefit cutoffs for disabled persons.

We hope this committee will express its concern for those recipients so they are not unfairly treated by a motivation to cut Federal spending and support legislation designed to provide an equitable review and transition.

The Nation's two largest health care programs, medicare and medicaid, which provide benefits to the poor and the elderly, are under constant attack because they are entitlements. We recognize the fiscal pressures these entitlement programs create, and we are supportive of the introduction of appropriate restraints. The entire third party reimbursement system in this Nation must be reformed. Shaving at the edges of the benefit programs that are designed for the truly needy will not do the job.

Quite frankly, we feel this is the last place to start trimming. Cost shifting or benefit reduction at the expense of the Nation's most vulnerable citizens just doesn't make sense. Providers of mental health services see the devastating results of this daily.

Finally, Mr. Chairman, a special concern of the mental health counselors centers around the elderly who, because of today's rapidly changing economic retirement outlook, are more confused and depressed and under more pressure and stress than most of us. Today, the elderly are incurring increasingly greater financial burdens for receiving health care services that do not even meet their needs. There is just no way we can expect the elderly to bear any more of this financial or mental burden. The aged individuals of our Nation deserve much, much better.

Thank you, Mr. Chairman.

[The statement follows:]

STATEMENT OF HARLEY M. DIRKS, WASHINGTON REPRESENTATIVE, AMERICAN MENTAL HEALTH COUNSELORS ASSOCIATION

The American Mental Health Counselors have some concerns about the proposed budget and the current fiscal policy.

As you are well aware, these are stressful times in America. Never, in recent history have Americans witnessed such high unemployment, runaway deficits, unbalanced budgets, and cutbacks that acutely effect the the poor, the sick, and the mentally unstable. Everyone is trying to adjust to these challenges. Some are, yet many are not. In times such as these, there is far greater incidence of mental stress and disorders. The rate of suicide and substance abuse continues to escalate. To deal with the results of this worsening pattern, a supportive effort is required, and skilled, well trained professionals are needed. I think it is very clear that now is the time to reverse the landslide reductions in mental health programs and begin an effort to provide the necessary means to effectively manage these problems.

Funds for Training

Although we support the research initiatives proposed in the President's Budget, we are disappointed to see only a small increase in research training, and the proposed elimination of clinical training for mental health. In FY 1984, we seek restoration of the FY 1983 figure of $21.5 million for clinical training and an increase of $2.3 million (15 percent) for research training, so training can be funded at $36.9 million. Even this increase will not adequately restore funding to levels of just a few years ago.

In the President's Budget, training dollars for drug abuse and alcoholism have been drastically underfunded. These funds for research training should be restored at least to levels that adequately reflect a maintenance of the program.

In view of the drastic reductions in funding for research training made two years ago, we should realize by now that these were mistakes, and should make every effort to restore these programs to respectable levels.

Block Grants

The American Mental Health Counselors Association is not totally dissatisfied with the general concept of the ADAMHA Block Grant. Yet, funding for this program remains a meritorious concern. Recently, Congress appropriated an additional $30 million in FY 1983 for the ADAMHA Block Grant in the Jobs Bill. This brought the FY 1983 Appropriation figure to $469 million. We support adding this $30 million to the FY 1984 baseline estimate of $439 million, and request an FY 1984 appropriation of $469 million.

Discretionary Programs

Discretionary programs are the foundation upon which our basic health service delivery, education, prevention, research, and training systems are built. In the absence of Federal support, neither state nor local governments, nor the private sector are financially capable of continuing these vital programs.

Health programs and Administrators are still reeling from the impact of the billions of dollars in cuts they suffered in FY 1982, and the millions lopped off in FY 1983. Now, before the full force of these cuts have been felt or examined, the Administration proposes to reduce by millions more the amounts necessary to carry out discretionary health programs in FY 1984. The American Mental Health Counselors Association is aware of the current distressing economic climate, however, we are also aware that discretionary health programs are among the most cost effective of our efforts, by reducing the need for greater future outlays for medical care. It is very well known that the current economic outlook weighs heavy on the minds of many. Now is not the time to eliminate opportunities before us in health. Now is the time to accelerate our efforts to meet the challenges we face in coming years.

It is our belief that there should be no further reductions in the realm of discretionary programs. These programs have been the source of public health innovation and progress, and have dealt with problems beyond the reach or authority of entitlement programs.

Disability Review

Congress has expressd a concern on the eligibility of disability recipients, but it appears that a chaotic review by the Administration has led to serious financial setbacks and abrupt benefit cut-offs for disabled persons. We hope this Committee will express its concern for these recipients so they are not unfairly treated by a motivation to cut Federal spending, and support legislation designed to provide an equitable review and transition.

Medicare/Medicaid Cuts

The nation's two largest health care programs, Medicare and Medicaid, which provide benefits to the poor and elderly are under constant attack because they are entitlements.

We recognize the fiscal pressures these entitlement programs create, and we are supportive of the introduction of appropriate restraints. The entire third party reimbursement system in this nation must be reformed. Shaving at the edges of benefit programs that are designed for the truly needy will not do the job. Quite frankly, we feel this is the last place to start trimming. Cost shifting or benefit reductions at the expense of the nation's most vulnerable citizens just doesn't make sense. Providers of mental health services see the devastating results of this daily.

Aging

Finally, Mr. Chairman, a special concern of the Mental Health Counselors centers around the elderly, who, because of todays rapidly changing economic and retirement outlook, are more confused and depressed, and under more pressure and stress, than most of us.

Today, the elderly are incurring increasingly greater financial burdens for receiving health care services that do not even meet their needs. There is just no way we can expect the elderly to bear any more of this financial or mental burden. The aged individuals of our nation deserve much, much better.

Thank you for this opportunity to express our concerns and for your continued support.

Senator PROXMIRE. Well, thank you very much, Mr. Dirks.

Mr. Dirks, on page 4, you say—under medicare and medicaid, "* * * we are supportive of the introduction of appropriate restraints." You are talking about the cost of these programs. "The entire third party reimbursement system in this Nation must be reformed."

We would appreciate any details that you could provide for the committee on that. I think you are aware of the fact that since the first full year of medicare in 1967, when we spent $3.4 billion, it has gone to $50.7 billion, an increase of fifteenfold.

At that rate—and there has been no letup in the pace of increase; it doubles every 4 years—at that rate by 15 years from now, it will be bigger than the entire Federal budget. This is including everything.

Obviously, we have to find some way of restraining the cost. It is hard to conceive of a more worthy program, a more needy program, but at the same time the costs have just gotten far beyond what we can possibly permit them to be in the future unless we act. So I am delighted to see that you suggest restraints. We would be delighted to have as much of that as you can give us.

Mr. DIRKS. Yes; we have submitted some material to the House Ways and Means Committee and the Senate Finance Committee, and we will submit those to this committee, also.

Senator PROXMIRE. All right. I appreciate that very much.

[CLERK'S NOTE.—The information is in the subcommittee's files.]

STATEMENT OF MORRIS ROSENBERG, PH. D., CONSORTIUM OF SOCIAL SCIENCE ASSOCIATIONS

Senator PROXMIRE. Our next witness is Dr. Morris Rosenberg, professor of sociology, University of Maryland, for the Consortium of Social Science Associations.

Dr. Rosenberg, we are honored to have you here.

Dr. ROSENBERG. Thank you, sir. I am testifying on behalf of the Consortium of Social Science Associations. We represent about 150,000 social and behavioral scientists throughout the United States. I have two objectives today. One is to provide a point of information; the other, a request. First, I would like to direct attention to the important role played by basic social and behavioral sciences research in understanding mental illness and in promoting mental health. Second, I would like to urge the subcommittee to provide increased support for the training of additional mental health researchers.

The seriousness of the problem of mental disorder in society is amply documented. It's estimated that about 15 percent of the American population needs some form of mental health care at any one time. About 25 percent of the American population are under sufficient emotional distress to be subject to clinically significant symptoms of depression and anxiety.

Furthermore, at least 15 percent of the patients seen in general medical practice are suffering from psychiatric or emotional problems. There are also major mental health problems associated with special groups such as school children, the elderly, people suffering from alcoholism and drug addiction, immigrant workers, and others. The cost to society in mental illness runs into the billions of dollars; the cost in human suffering is incalculable.

The evidence is clear in showing that sociocultural factors play a more important role in mental disorder than in any other type of disease, and are inextricably interwoven with every phase and aspect of mental health. Research demonstrates that who becomes a mental patient, which treatment is provided, and the nature and success of that treatment are strongly influenced by sociocultural variables.

Despite these facts, this administration is choking social science research to the point of suffocation. Two years ago, NIMH made 46 new awards for social science research. Last year, this number dropped to 13. This year, only 14 new awards were made. This tiny number of awards is intended to cover mental health research in crime and delinquency, epidemiology, work and mental health, behavioral sciences, and several other areas. It is apparent that social science support is rapidly reaching the vanishing point.

This is incredibly shortsighted. Social science research is absolutely essential for understanding the etiology, epidemiology, and social consequences of mental disorder and for reducing the incidence and prevalence of mental disorders in society.

I believe that this policy rests on a fundamental misunderstanding of the nature of mental disorder as well as of social research. Mental disorders, unlike most other medical disorders, involve disturbances in interpersonal relations and are closely associated with such social problems as alcoholism, drug addiction, delinquency, crime, family rupture, and many more. It is apparent that biological, psychological, and social science research are all essential for dealing with the widespread problem of mental disorder in society.

Second, I would like to urge you to increase the research training budget at NIMH by $5 million in fiscal 1984. If the President's budget is adopted, 1984 funding for research training will be 18 percent below that of 1981. Between 1981 and 1983, the number of trainees will decline by about one-third. In my view, by saving money now, we are mortgaging our future. A scientist is not created overnight. Scientific training involves years of committed, painstaking work.

We need such training because science progresses when the new fact encounters the prepared mind. I admit that it is difficult to measure the discoveries that will not be made, the suffering that will not be alleviated, if support is not provided, but we know that these effects are real, and that they have significant consequences for broad segments of our society. If one skimps on research training today, we can be sure that the future costs to us will vastly exceed the current modest savings.

Senator PROXMIRE. Thank you very, very much, Dr. Rosenberg, for a fine statement. We very much appreciate it. Your statement will be included.

[The statement follows:]

STATEMENT OF MORRIS ROSENBERG, PH. D.

Chairman Weicker and Members of the Subcommittee: My name is Morris Rosenberg. I am Professor of Sociology at the University of Maryland at College Park. I am testifying on behalf of the Consortium of Social Science Associations (COSSA), which represents over 150,000 social and behavioral scientists throughout the United States.

I appreciate having the opportunity to testify before the Subcommittee on the FY 1984 budget for the National Institute of Mental Health (NIMH) and want to thank the members of this Subcommittee for their continued support of NIMH's successful research programs.

I come before the Subcommittee with two objectives--one a point of information, the other a request. First, I would like to explain the important role played by basic social and behavioral science research in understanding mental illness and in promoting mental health. Second, I would like to urge the Subcommittee to provide increased support for the training of additional mental health researchers.

Contribution of Social and Behavioral Science to Mental Health Research

Human beings are quintessentially social beings. Deprived of companionship, our behavior deteriorates. Most of us are simultaneously members of several social networks -- our family, friends, neighbors, and fellow employees. Indeed, the very sense of our own identity is forged out of these important elements. Mental health research that focuses only on understanding underlying physiological and biochemical mechanisms associated with mental illness and that does not simultaneously investigate social factors that precipitate mental breakdowns or exacerbate mental illness cannot tell us what we need to know about its prevention. Indeed, knowledge of the physiological and biochemical mechanisms underlying mental illness alone is insufficient in that it does not reveal what causes these pathological physiological states to develop. In fact, one cannot assume that they "cause" aberrant mental states because the relationship can work in the other direction as well. Indeed, changes in social psychological processes can have physiological effects as well as the reverse. The determinants of human behavior are a complex mix of physical and environmental factors. For a research program to emphasize one at the expense of the other is to court failure.

All too often mental illness is thought of as a series of discrete disease states -- schizophrenia, manic-depressive disorder, depression, etc. -- having possible biological causes. Yet the lives of millions of others are also destroyed or incapacitated by homicides, suicides, child abuse, alcoholism, drug abuse, and a host of psychosomatic illnesses and problems that affect the respiratory system, the intestines and the back. These conditions, although often not classified as mental illness, represent definite breakdowns in mental health. They most often result from stress. It is a perfectly legitimate goal of a national institute dedicated to preventing mental illness and promoting mental health to concern itself with identifying major sources of stress which, when sustained, cause large numbers of particular classes of people to fall apart or to become social problems by striking out blindly at their children, their spouses, or others. These areas, which are often difficult to study, comprise a legitimate arena of mental health research initiatives and represent a research area where social and behavioral scientists can and do make major contributions. Indeed, there have been important methodological developments in the social sciences in recent years that hold real promise for our being able to understand social phenomena with greater precision and better understanding.

As you are no doubt aware, two years ago the Administration requested that NIMH cease supporting social research. As a result, the August 1981 announcement for NIMH Research Support

Programs was revised to require that applications for social and behavioral science research grants be "clearly relevant to mental illness and health" in order for research proposals to be considered by the Institute. These new strictures, in concert with the well-publicized Administration directive against social research at NIMH, resulted in a precipitous (80%) drop in social and behavioral science research applications as scientists assumed that NIMH would no longer be supporting research in these disciplines. It has taken two years and much education to persuade researchers that funds are still available for social science research as long as studies are explicitly related to mental health.

Dr. Pardes, Director of NIMH, has on several occasions reiterated his support for the social and behavioral science research programs at NIMH. COSSA and its members appreciate his vision and his support. I fear, however, that the damage wrought by the Administration's initial misunderstanding of the nature and importance of social research at NIMH has not yet been overcome. I also worry that contemporary proclivities for simple solutions to complex problems will favor the support of biologically-oriented research at the expense of the social and behavioral sciences. We in the social and behavioral sciences recognize the important contributions biological research has to make to understanding mental illness. Today, however, I am asking Members of Congress to assure that NIMH maintain a balanced program of research, one which acknowledges the important contributions the social and behavioral sciences have made to understanding and preventing mental illness.

Need for Increased Support for Research Training

As I mentioned earlier, I come before you today also to make a request. I urge that you consider increasing the research training budget at NIMH by $5 million for FY 1984.

Congress has recognized the importance of mental health research by annually raising the level of support for NIMH. It is distressing to note, however, that while extramural research funds at NIMH will rise by 9 percent between FY 1981 and FY 1984 if the President's budget is adopted, funding for research training will decline by 18%. Excellence in mental health research cannot be achieved without well-trained mental health researchers. I suggest that by overlooking research training needs the Congress is constructing a well-designed research edifice, but is setting it on a very weak foundation.

In FY 1981 NIMH supported over 1,200 mental health research trainees at a cost of $19 million. In FY 1983, it is estimated that only 885 trainees can be supported, a reduction of one third. In part this cutback is due to an increase in the proportion of postdoctoral fellows who are supported, but the more important cause is the substantial reduction in the NIMH budget for research training.

Let me take just a moment to describe for you the degree to which research training in the social and behavioral sciences has been adversely affected by budget reductions. In FY 1976, the Division of Manpower and Training awarded 100 individual predoctoral fellowships to sociology and anthropology students alone. Last year, FY 1982, the total number of predoctoral fellowships in the social and behavioral sciences had declined to 7. Of those, only 3 were awarded to sociology and anthropology students. The other 4 went to students in psychology.

NIMH estimates that the annual support of 1200 to 1500 mental health research trainees for all disciplines would be adequate to sustain the supply of mental health researchers. It has been said that science advances when new facts come into contact with trained minds. The future of mental health research depends on the continued availability of trained researchers.

If the proposed budget for research training at NIMH were increased by $5 million over the President's recommendation of

$15.5 million, the increase would almost restore the research training program to its level of funding in FY 1981 (in constant dollars) and would increase the number of individuals supported to 1,163. This is still well below the optimal level of 1,500 but well above the 880 that could be supported by the figure recommended in the President's budget. It is important to note that an increase would enable the Institute to start a new research training program in prevention research.

I would like to thank the Subcommittee for the opportunity to testify today. I hope that I have succeeded in convincing you of the important role played by social and behavioral science research in the area of mental health and that you will agree to increase by $5 million the NIMH research training budget so that this nation can be assured of a continuing supply of well-trained mental health researchers.

STATEMENT OF GORDON L. STEINHAUER, MEMBER, BOARD OF DIRECTORS, NATIONAL COUNCIL ON ALCOHOLISM

ACCOMPANIED BY JAY LEWIS, DIRECTOR, PUBLIC POLICY STAFF, NATIONAL COUNCIL ON ALCOHOLISM

Senator PROXMIRE. Our next witness is Gordon Steinhauer, a member of the board of directors of the National Council on Alcoholism. Mr. Steinhauer, would you identify the distinguished gentleman who is with you, for the record?

Mr. STEINHAUER. Yes, sir. Accompanying me today is Mr. Jay Lewis, who is the director of our public policy staff for the National Council on Alcoholism.

Senator PROXMIRE. Very good.

Mr. STEINHAUER. On behalf of the National Council on Alcoholism, I would like to thank you, Mr. Chairman, for the opportunity to express our views on the funding of the Federal alcoholism effort during the fiscal year beginning October 1.

I want to reemphasize that my name is Gordon Steinhauer. In a voluntary role, I am a member of the national board of directors of the National Council on Alcoholism, and serve as the immediate past chairman of that board.

In my employment, I am in health administration, and I am currently the vice president of St. Lawrence Hospital in Lansing, Mich. NCA, with more than 220 affiliates in communities across the Nation, is the oldest and largest association of volunteers in the alcoholism field.

The administration's request for NIAAA next year would increase the research budget from $33.3 million to $45.8 million. The NCA Board of Directors went on record last February with a resolution applauding the administration's recognition of the crucial importance of enhanced research funding in providing new understanding of the problems of alcoholism and alcohol abuse. We vigorously support the administration's requested level of support for NIAAA research next fiscal year.

NCA is especially supportive of the current high priorities NIAAA is placing on prevention and treatment assessment research, both of which we believe can furnish rewarding avenues of investigation. NCA also supports increased funding of traditional biomedical and psychosocial studies, which, as nurtured by NIAAA over the past 12 years, have earned the field of alcohol studies a well-deserved reputation for excellence, on a parity with older, more established scientific fields.

NCA urges the subcommittee to consider increased funding for NIAAA's research training program, for which the administration requested only $1.2 million in fiscal 1984. We believe that pools of technically proficient investigators are vital to quality research, and enrichment of these reservoirs of talent is particularly important for the newly emerging areas of prevention and treatment research. At the same time, we favor reinstatement of the clinical training programs at NIAAA.

With respect to the Alcohol, Drug Abuse, and Mental Health Administration service block grants, NCA supports a level of funding up to the full authorization, of the $532 million. We believe that the network of treatment services supported by the block grant is being severely overtaxed by increased client loads at a time when State and local resources are shrinking. Moreover, the trial of alcohol and other problems, exacerbated by the economic hard times, will continue for years after the Nation's economy has recovered.

NCA is also adamantly opposed to the proposed transfer of the ADM block to the Office of the Assistant Secretary for Health. Some measure of Federal oversight is demanded in the interest of accountability, and this oversight should be exercised at the level of Alcohol, Drug Abuse, and Mental Health Administration by personnel knowledgeable about the program areas addressed.

Finally, NCA would like to comment on the issue of the organizational integrity of NIAAA within the structure of ADAMHA. This committee raised the issue 2 years ago in urging that consideration be given to transfering the research programs of ADAMHA institutes to the National Institutes of Health. We believe such a move would have a negative impact on the cause of alcoholism field and historic mission.

Although biomedical research is a crucial component of the effort to curb alcoholism and other alcohol-related problems, alcoholism, unlike most other disorders under the umbrella of NIH, has unique ramifications in areas of social and health policy.

The predominantly biomedical atmosphere prevailing at NIH would be an alien and stifling environment, not only for the increasingly important areas of prevention and treatment research, but for the general public education and prevention activities that constitute an important part of the NIAAA mandate.

Thank you again for the opportunity to testify in support of the Federal alcoholism program, an effort in whose legislative genesis NCA actively participated in, more than 12 years ago, and one which we believe has accomplished measurable good in the truest sense of the word: the salvaging of human lives.

Thank you.

Senator PROXMIRE. Thank you very, very much, Mr. Steinhauer.

Mr. Lewis, did you want to add anything?

Mr. LEWIS. No; thank you, Senator.

Senator PROXMIRE. Very good. Well, thank you, gentlemen. I very much appreciate your statement. It's certainly an excellent statement.

Again, I wish there was more time for discussion, but I think you understand the——

Mr. STEINHAUER. Yes, sir. Thank you, Senator Proxmire.

Senator PROXMIRE [continuing]. Time constraints. Thank you.

[The statement follows:]

STATEMENT OF GORDON L. STEINHAUER

On behalf of the National Council on Alcoholism, I would like to thank you, Mr. Chairman and members of the Subcommittee, for the opportunity to express our views on funding for the federal alcoholism effort during the fiscal year beginning next Oct. 1. My name is Gordon Steinhauer, and in my voluntary role, I am a member of the Board of Directors of NCA, of which I am immediate past Chairman, and serve also as current Co-Chairman of the Public Policy Committee. My profession is in health administration, and I am Vice President of St. Lawrence Hospital, Lansing, Michigan.

NCA, with more than 220 affiliates in communities across the nation, is the oldest and largest association of volunteers in the field of alcoholism--dedicated to eradicating the stigma surrounding the disease of alcoholism, making treatment accessible, and promoting activities to reduce the social and economic toll wreaked by alcoholism and alcohol-related problems. In this connection, we are firmly committed to the proposition that the problem of alcoholism and alcohol abuse is of such sweeping dimensions that it constitutes a major public health threat and as such demands the application of public funds for research, prevention and treatment. However, NCA itself does not accept government funds, relying solely on contributions from the private sector.

The magnitude of the nation's problems with alcohol was recently pointed up in a case study conducted for the Congressional Office on Technology Assessment on "The Effectiveness and Costs of Alcoholism Treatment." The case study said the 1982 economic costs of alcohol abuse could approach $120 billion in terms of lost productivity, the burden on the health care system, criminal justice, motor vehicle crashes and other costs. Estimating that as many as 85 percent of those suffering from alcoholism are not being treated, the study concluded that the problem of alcoholism and alcohol abuse is too serious, in light of its impact on the nation, to be ignored.

That research can contribute to a reduction in these costs was one of the conclusions of the Institute of Medicine in its landmark report in 1980, "Alcoholism, Alcohol Abuse and Related Problems: Opportunities for Research." Declaring that alcohol research has been "grossly underfunded," the IoM stated that "alcoholism is just too costly to this country for us not to spend money on alcohol research." It recommended that funding for the research program of the

National Institute on Alcohol Abuse and Alcoholism be increased by 50 percent annually over a three-year period.

The Administration's request for NIAAA next fiscal year represents an attempt to follow through on the IoM's recommendations by increasing the research budget from the current $33,281,000 to $45,790,000.

The National Council on Alcoholism, by action of its board of directors in February, went on record with a resolution stating its whole-hearted accord with the IoM recommendation and applauding President Reagan and his Administration's recognition of the crucial importance of enhanced research funding in providing new understanding of the problems of alcoholism and alcohol abuse. We vigorously support the Administration's requested level of support for NIAAA research in fiscal 1984.

NCA is especially supportive of the current high priorities NIAAA is placing on prevention and treatment assessment research, both of which we believe can furnish rewarding avenues of investigation.

Treatment and treatment assessment research is increasingly important in light of emerging issues surrounding third-party reimbursement, both private and public. With direct federal funding of treatment services eliminated and support for such programs by state and local agencies curtailed, third-party payment systems must assume a larger role in making treatment available to those who need it. The case study by the Office of Technology Assessment concluded that although the costs of not reimbursing for alcoholism treatment probably exceed the costs of paying for such treatment, there is a clear need for more systematic specification of which patients would be best serviced by which of the available alcoholism treatment systems. Information on this issue, it said, can be developed through available research techniques. NCA would urge that a minimum of $5 million within the requested level for NIAAA research next year be set aside for treatment and treatment assessment research, and suggest that the Appropriations Committee consider language directing such an allocation in its report on the bill.

Prevention research also represents an area worthy of expanded attention, focusing as it does on strategies to curb the range of negative consequences of alcohol use, most tragically exemplified by the toll of young lives lost in alcohol-related traffic accidents. In addition to increased support for developing and testing alcohol education methods, NCA endorses plans by NIAAA to step up investigations in the public policy arena, including the effects of legal drinking age revisions, changes in alcohol taxes and other measures influencing the availability of alcoholic beverages. Last July, NCA announced adoption of a bold new prevention position in support of increased taxation of alcoholic beverages, health warning labels, voluntary curbs on advertising, and a uniform legal drinking age of 21 throughout the states. Although scholarly documentation of the beneficial effects of such steps is already impressive, NCA welcomes further inquiry into this crucial and relatively new area of policy research. We believe such studies can furnish promising leads to the formation of a comprehensive approach by federal, state and local governments in the regulation of alcoholic beverage sales, distribution and marketing--now largely a polyglot of contrasting rules and statutes administered by 50 diverse alcoholic beverage control agencies at the state level. NCA urges that at least $3.5 million of the requested amount for NIAAA research be devoted to studies on public policy and other prevention approaches.

The bulk of NIAAA research dollars is channeled into traditional biomedical and psychosocial studies which, as nurtured by NIAAA over the last 12 years, have earned the field of alcohol studies a well-deserved reputation for excellence on a parity with older more established scientific fields. Research into genetic factors predisposing individuals to a susceptibility to alcohol is further bolstering the scientific acceptance of alcoholism as a disease of physiological origin, and studies on biochemical differences between alcoholics and non-problem drinkers not only validate the fact that alcoholism is a disease but offer exciting possibilities for identifying individuals at risk before onset of the disease. Research on the effects of alcohol on the fetus, supported by NIAAA, is one of the most dramatic examples of a direct pay-off in terms of research findings being translated into public awareness as well as clinical measures to prevent this most preventable cause of mental retardation and other congenital defects. These, of course, are just a few of the significant research endeavors which have contributed to the quest for answers to what in the past has been such a baffling and mysterious health problem.

NCA also supports NIAAA's alcohol clinical research program, which will become fully operational in 1984 under the Administration's budget request, and looks forward to the development of improved diagnostic and therapeutic techniques as a result of work to be conducted at the new facility. We are pleased to learn that no alcohol will be administered experimentally to patients in the clinical research program. NCA hopes this policy will continue under future administrations.

The NIAAA research training program dovetails with its research program by attempting to reflect the same priorities in the training of investigators. NCA urges that in light of the new priorities in the areas of treatment, treatment assessment and prevention research, this Committee give serious consideration to increasing the Administration's requested support for research training next year--$1,202,000, essentially the same level as 1983. Pools of technically proficient investigators are vital to quality research, and enrichment of these reservoirs of scientific talent is particularly important for the newly emerging areas of treatment and prevention research.

At the same time, NCA favors the reinstatement of the clinical training program at NIAAA, for which the Administration requested no funds in fiscal 1984. NCA is disappointed that Congress failed to appropriate funds for NIAAA clinical training during the current year, while providing support for the clinical training program of the National Institute of Mental Health. We urge that the clinical training activities of all three ADAMHA Institutes be adequately supported. At the minimum, we suggest that funds be added in 1984 for the NIAAA career teachers program, which, although never large in budgetary terms, has made a impressive contribution to medical education in alcoholism by supporting faculty members at major medical schools to provide a focus on alcohol subjects in their curricula.

Under the Administration's request, NIAAA would receive only $10,981,000 for direct operations next year. This item provides support not only for standard administrative activities but for a range of important functions not encompassed under the research authorities. These embrace research dissemination, policy analysis, technical assistance, public education and prevention activities, including support for the National Clearinghouse for Alcohol Information. Moreover, ongoing support for the teenage alcohol abuse initiative launched by former HHS Secretary Richard Schweiker and renewed with the commitment of the present Secretary, Margaret Heckler, is derived from this line item. NCA would be very supportive of an increased appropriation to accommodate an expansion of these activities and to obviate the need for reprogramming or supplemental requests next year.

NCA joins with other organizations in the alcoholism, drug abuse and mental health fields to urge an increase in the appropriations for the Alcohol, Drug Abuse and Mental Health (ADM) Block Grant, for which Congress voted a $30 million add-on in the recently enacted jobs and recession-relief bill. The network of treatment services supported by the block grant are being severely overtaxed by increased client loads at a time when state and local resources are shrinking. Moreover, the trail of alcohol and other problems excacerbated by economic hard times will continue for years after the current recession is ended. Therefore, NCA believes the $469 million provided this year for the ADM block grant should be seen as a rock bottom base for next year's appropriations. We would support funding up to the full authorization of $532 million for the ADM block.

NCA is adamantly opposed to the proposed transfer of the ADM block to the Office of the Assistant Secretary for Health, where its administration would be consolidated with three other health block grant programs. The Department of Health and Human Services explains that this move is "consistent with Administration policy to reduce unnecessary federal oversight of state and local programs." We submit that a some measure of federal oversight is demanded in the interests of accountability, and that this oversight should be in the hands of personnel who are knowledgeable about the program areas of the ADM block--not only to ensure efficiency in the distribution of the funds but to enable expert technical assistance to the states.

Finally, NCA would like to comment on the issue of the organizational integrity of NIAAA within the structure of the Alcohol, Drug Abuse and Mental Health Administration. This Committee raised the issue two years ago in urging that serious consideration be given to transferring the research programs of ADAMHA Institutes to the National Institutes of Health. As you know, the present ADAMHA mechanism has been in operation since 1973, and has on the whole afforded a smooth working arrangement under which the three Institutes have operated with maximum autonomy in their areas of special interest while benefitting from administrative and programmatic coordination in areas of overlapping concern. We believe that any dismantling of ADAMHA, by moving its research components to NIH, would be counter to the maxims of good government.

But of paramount concern to NCA is what we predict would be a calamitous effect on the cause of the alcoholism field and its historic mission. As we have indicated in our testimony today, biomedical research is a crucial component of the effort to curb alcoholism and other alcohol-related problems. However, unlike most of the diseases and disorders addressed by NIH, alcoholism has unique ramifications and implications extending into broad areas of social and health policy concerns. The predominately biomedical atmosphere prevailing at NIH would be an alien and stifling atmosphere not only for the increasingly important areas of prevention and treatment research, but for the general public education and prevention activities that constitute a unique part of NIAAA's mandate. A shift of NIAAA to the big research campus of NIH, where it would be subsumed into the ranks of some 18 other Institutes, would result in a severe diminution of the federal presence in alcoholism--a public health problem of the first rank which demands the highest visibility. NCA fears that a transfer of NIAAA to NIH would accomplish nothing beyond relegating the Institute to a kind of bureaucratic exile and ultimately its demise as a significant focus of federal concern.

Thank you again for the opportunity to testify in support of the federal alcoholism program, an effort in whose legislative genesis NCA actively participated more than 12 years ago and which, we believe, has accomplished palpable good in the truest sense of the word, the salvaging of human lives.

STATEMENT OF OLIVE JACOB, DEPUTY DIRECTOR, NEW YORK DIVISION OF ALCOHOLISM AND ALCOHOL ABUSE, NATIONAL ASSOCIATION OF STATE ALCOHOL AND DRUG ABUSE DIRECTORS

ACCOMPANIED BY NANCY RECORD, STAFF MEMBER AND CONGRESSIONAL LIAISON, NASADAD

Senator PROXMIRE. Our next witness is Olive Jacob, deputy director, New York Division of Alcoholism and Alcohol Abuse, National Association of State Alcohol and Drug Abuse Directors, and, Ms. Jacob, if you would introduce the young lady who is with you, we would appreciate it very much.

Ms. JACOB. This is Nancy Record. She is staff member and congressional liaison for NASADAD.

Senator PROXMIRE. Very good.

Ms. JACOB. Mr. Chairman, the National Association of State Alcohol and Drug Abuse Directors, NASADAD, is pleased to have this opportunity to present a statement on the President's fiscal year 1984 budget request for the Alcohol, Drug Abuse, and Mental Health block grant, and the programs of the National Institute on Alcohol Abuse and Alcoholism, and the National Institute on Drug Abuse.

As a member of the NASADAD legislative committee, I am here today to urge members of the subcommittee to continue to support these important programs which assist the States in their efforts to prevent and treat alcoholism and drug abuse. Overall, the State alcohol and drug abuse agencies have made a smooth transition from the previous Federal categorical alcohol and drug project and formula grant programs to the Alcohol, Drug Abuse, and Mental Health block grant program.

The smooth transition is in part due to the fact that the State alcoholism and drug abuse agencies were already administering three-fourths of the programs which were folded into the alcohol and drug portion of the ADM block grant program. The funding reductions accompanying the block grant were supposed to be balanced by administrative cost savings associated with the ADM block grant and streamlined and efficient management.

In our case, this supposition was not applicable. The alcohol and drug programs were penalized for having been one step ahead. In fiscal year 1980, the base year for the alcohol and drug portion of the ADM block grant, Federal appropriations for the alcohol and drug abuse project and formula grant programs totaled $332 million.

In fiscal year 1983, the alcohol and drug portion of the block grant equaled only $223 million, a 33-percent reduction from fiscal year 1980 levels, without adjusting for inflation. If the inflation rates are taken into account, current Federal funding levels for alcohol and drug treatment and prevention services represent a 42-percent reduction, in real dollars. Indeed, the Federal support appears to be nearly cut in half in the short space of 3 years.

Even if the Congress decides to appropriate the full amount authorized for the ADM block grant program in fiscal year 1984, $532 million, the alcohol and drug abuse portion of the total would still represent a 20-percent decrease from the fiscal year 1980 funding level. When adjusted for inflation, the authorization level represents a 29-percent decrease from fiscal year 1980 funding levels.

Many States with careful budget planning combined with a temporary overlap of Federal funding have been able to maintain a minimum level of services even with the significant reduction in Federal support. This was because in fiscal year 1982 many States received their fiscal year 1982 block grants award, prior to the expiration of their previous fiscal year's project and formula grants. This phenomenon was due to the unforeseen delay of previous Federal grant awards in many States where the fiscal year award was not made until 6 months after the beginning of the fiscal year.

As a result, there existed a temporary overlap of Federal funds. and some States were able to postpone the negative impact of the decrease in Federal funding for alcoholism and drug abuse services which accompanied the ADM block grant. With creative planning, many States have been able to stretch this cushion into the 1983 fiscal year, but it will go no further.

Beginning in fiscal year 1984, many programs in the 50 States and U.S. territories will close their doors. In a time when these programs are needed the most, State revenues are simply not available to bridge this funding gap, since State coffers are being drained by the provision of minimal welfare and social services benefits to the unemployed and their families.

With our written testimony, we are providing you with the results of a survey conducted by NASADAD on the status of State alcohol and drug abuse service systems. Many of the States have increased their expenditures for prevention programs, a change which appears to be related to the ADM block grant requirement that 20 percent of the ADM block grant dollars be allocated for prevention. In many States, the capacity to support treatment services declined in fiscal year 1983, even though the perceived need in those States had increased due to economic conditions and indeed changing age cohorts as that relates to alcoholism. In several States, there has been a change in the type of treatment services provided, with less residential care and more early intervention-type care.

Of major importance, however, is the fact that over 94 percent of the States responding to the NASADAD survey reported that the unmet need for treatment and prevention services exists within those States. Thus, even though the State may be able to maintain current services, this is not enough. There are still thousands of individuals who need and could benefit from some type of prevention or treatment services.

NASADAD is not only concerned about the President's budget request for the ADM block grant, but also the proposal to transfer administrative responsibility for the program to the Office of the Assistant Secretary of Health. It does not make sense for responsibility for these programs to be transfered from the agency and personnel who have historically taken responsibility for the Federal role in alcoholism and drug abuse to the Office of the Assistant Secretary of Health, for the sake of convenience. It is not convenient for the States.

NASADAD wishes to express its support for the key leadership role which both NIAAA and NIDA must continue to play at the Federal level. NASADAD applauds the Institute's efforts to disseminate important research findings relevant to alcohol and drug abuse prevention and treatment services, and encourages expansion of their technical assistance activities to State, local, and private organizations.

The administration's request for a continued, significant increase in the scope and capabilities of the NIAAA and NIDA research programs on these serious public health problems and the accompanying increase in the requested funding levels is also supported by NASADAD. The Federal investment in research may yet reach a level commensurate with the burden of these illnesses on the American people.

NASADAD is particularly concerned that the NIAAA and NIDA clinical training efforts were eliminated in the fiscal year 1983 appropriations process. The national alcohol and drug abuse training systems represented over a decade of coordinated effort by the Federal Government, State alcohol and drug abuse authorities, and local programs personnel. The States cannot make it alone.

It seems particularly unsettling that the Federal Government does not continue to support an existing training network, which only requires a minor financial contribution from the Federal Government—but a contribution which can make or break the system. NASADAD requests that the members of the subcommittee reevaluate their decision to eliminate funding for the NIAAA and NIDA clinical training programs. An appropriation of at least $5 million for each institute in the form of grants to the States for revitalization of statewide training networks should assist State efforts to repair the training network, which has been severely crippled by the Federal Government's elimination of funding support.

In closing, we encourage subcommittee members to carefully review the material which we have submitted, and which documents the decline of the Federal support for alcohol and drug abuse services since fiscal year 1980. During the 1970's, the statewide service systems made great strides in efforts to reduce and prevent alcoholism and drug abuse among our children, friends, and colleagues. In recent years, however, these service systems have made little progress, since Federal funding support was reduced by almost half.

Please reconsider your level of support for these programs, and assist the States in their efforts to treat and prevent alcoholism and drug abuse. Thank you.

Senator PROXMIRE. Thank you very much, Ms. Jacob. It is a very effective statement. I thought it was an especially excellent explanation of the difficulty for the alcohol and drug abuse program given the low level of funding and the failure to provide adequate funding.

I notice in your addenda here, your attachments, you have changes in status of service systems in fiscal year 1983, you have 42 States, I think, not including Wisconsin. Why are we left out?

Ms. JACOB. I believe, if you turn to the last page——

Senator PROXMIRE. The last page was something else. Last page are projections. In projections, we are included.

Ms. JACOB. Yes; I think there were some answers that we didn't have on the survey form, but I would like to point out, Senator, that many of the States have, as a first choice, sought to take cuts in the staffing of the State agencies, and I believe that in your State, in fiscal year 1983, the staff of your State alcohol and drug agency was reduced from 80 people to 25; and also, that with the expected continuing decrease in State moneys and services, due to a $2 billion budget deficit, it looks very difficult for Wisconsin to pick up.

Senator PROXMIRE. Projections. The first part was a kind of report on what's been done, and the second part was projections on what we might expect.

Ms. JACOB. Right.

Senator PROXMIRE. And if you could give us for the record anything you have on that, I would appreciate it very much. We are very conscious of the alcohol problem in Wisconsin. We are a great beer State, as you know, one of the great assets. Some people would prefer our stressing the fact that we're the dairy state, but—— [Laughter.]

[CLERK'S NOTE.—The information was not received.]

Senator PROXMIRE. But thank you very much. Excellent presentation.

Ms. JACOB. I would like to add just one point, Senator, and that is in addition to the pressures on the system from unemployment, that as you are aware with both the Federal emphasis on stricter drinking while intoxicated—I mean, driving while intoxicated, laws, and the same on the State level, that there is a tremendous increase in demand for services related to referrals from drinking driver programs.

Senator PROXMIRE. Do you have any position on the proposal that we have a national drinking age of 21, instead of varying as much as it does, in various States?

Ms. JACOB. Well, there have been a number of changes in the States over the last few years. In fact, in New York we have just gone for the first time since Prohibition from 18 to 19.

We believe there is a need for some detailed studies of what happens in terms of these changes——

Senator PROXMIRE. Let me interrupt to say the reason why the national approach might be justified is because of the tendency for people to drive across State borders.

Our State has an 18-year age, and the surrounding States have 19, and the result is that we have had people killed, increases in tragedies that result from this, and a national age might be helpful.

Ms. JACOB. Yes.

Senator PROXMIRE. Of course, if you raise it to 21, that would take care of the high school students.

Ms. JACOB. I think a consistent age would be helpful, and we do have data in New York, particularly with the crossover from Pennsylvania, that would illustrate your point.

Senator PROXMIRE. Ms. Record, do you have anything you would like to add?

Ms. RECORD. No, sir.

Senator PROXMIRE. Very good.

Ms. JACOB. Thank you.

Senator PROXMIRE. Thank you very much.

[The statement follows:]

STATEMENT OF OLIVE JACOB

The National Association of State Alcohol and Drug Abuse Directors (NASADAD) is pleased to have this opportunity to present a statement for the Subcommittee hearing record on the President's FY 1984 budget request for the Alcohol, Drug Abuse and Mental Health (ADM) Block Grant and the programs of the National Institute on Alcohol Abuse and Alcoholism (NIAAA) and the National Institute on Drug Abuse (NIDA). As a member of the NASADAD Legislative Committee, I am hear today to urge members of the Subcommittee to continue to support these important programs which assist the States in their efforts to prevent and treat alcoholism and drug abuse. First, I would like to provide you with some background information on the State Alcohol and Drug Abuse agencies.

State Alcohol and Drug Abuse Agencies

The State Alcoholism Agencies and the Single State Agencies for Drug Abuse Prevention were created by the States in response to Congressional action in the Comprehensive Alcohol Abuse and Alcoholism Prevention, Treatment and Rehabilitation Act of 1970 and the Drug Abuse Office and Treatment Act of 1972, respectively, to have sole responsibility in the States to plan and administer a Statewide alcoholism and/or drug abuse prevention and treatment network.

Under the Omnibus Reconciliation Act of 1981, which created the ADM block grant and significantly revised the purpose of NIAAA and NIDA, the mandate for Single State agencies was repealed. However, I am pleased to inform you each State has chosen to retain this State structure in order to effectively coordinate State alcohol and drug treatment and prevention services including administration of the relevant portion of the Federal ADM Block Grant.

Alcohol, Drug Abuse and Mental Health Block Grant

Overall, the State alcohol and drug abuse agencies have made a smooth transition from the previous Federal categorical alcohol and drug project and formula grant programs to the Alcohol, Drug Abuse and Mental Health block grant program. The smooth transition is in part due to the fact that the State drug agencies had been receiving their Federal project grant dollars through a mechanism similar to the block grant for several years -- the Statewide services grant -- and were already responsible for allocating and monitoring the Federal drug abuse project grants. Also, at the time of the ADM block grant authorization, Federal officials were considering switching to a Statewide services funding mechanism for the Federal alcoholism project grants, which at that time were being administered by NIAAA. In fact, five States were participating in a demonstration project testing the feasibility of the Statewide services grant mechanism for the alcoholism project grants. Both the alcohol and drug abuse formula grants were awarded directly to the State alcohol and drug agency, which in turn allocated the dollars where they were needed most.

Since the State alcoholism and drug abuse agencies were already administering three-fourths of the programs eventually folded into the alcohol and drug portion of the ADM block grant program, the basis for the supposed administrative cost savings associated with the ADM block grant - streamlined and efficient management - was only applicable to the alcoholism project grants in the 45 States which were not participating in the demonstration project. The funding reductions accompanying the block grant were supposed to be balanced by the increased costs savings realized from the new funding and administrative mechanisms. Unfortunately, for the alcohol and drug services programs the supposition was not relevant. Rather they were penalized for having been one step ahead.

In FY 1980 (the base year for the alcohol and drug portion of the ADM block grant), Federal appropriations for the alcohol and drug abuse project and formula grant programs totalled $332 million. In FY 1983 the alcohol and drug portion of the block grant equalled only $222.8 million - a 33 percent reduction from FY 1980 levels without adjusting for inflation. If the inflation rate of 10.4 percent in 1981 and 6.1 percent in 1982 is taken into account, current Federal funding levels for alcohol and drug treatment and prevention services represent a 42% reduction in real dollars. Indeed, the Federal support appears to have been nearly cut in half in the short space of three years.

Recognizing the increased demand for alcohol and drug treatment services by the unemployed, members of Congress added $30 million to the ADM block grant FY 1983 appropriation in the recently enacted package of jobs and humanitarian aid for the unemployed. Even with this increase of $15.2 million (the alcohol and drug portion of the ADM block grant equals 50.76% of the total), Federal funding for the alcohol and drug services programs, when adjusted for inflation, has decreased 33% from the FY 1980 level.

If the Congress decides to appropriate the full amount authorized for the ADM block grant program in FY 1984 - $532 million - the alcohol and drug abuse portion of the total would still represent a 20% decrease from the FY 1980 funding level (when adjusted for inflation, the authorization level represents a 29% decrease from FY 1980 funding levels).

Many States, with careful budget planning combined with a temporary overlap of Federal funding have been able to maintain a minimum level of services even with the significant reduction in Federal support. In FY 1982, many States received their FY 1982 block grant award prior to the expiration of their previous fiscal year's project and formula grants. This phenomenon was due to the unforseen delay of previous Federal grant awards in many States where the fiscal year award was not made until six months after the beginning of the fiscal year. For example, State X applied for and received its FY 1982 block grant quarterly allocation on October 1, 1982. However, State X's FY 1981 Statewide services annual grant award had not been awarded until March 1982 (six months after the beginning of FY 1981). As a result, there existed an overlap of Federal Funds and the State was able to postpone the negative impact of the decrease in Federal funding for alcoholism and drug abuse services which accompanied the ADM block grant. With creative planning, many States have been able to stretch this cushion into the 1983 Fiscal Year, but it will go no farther. Beginning in FY 1984, many programs in the 50 States and U.S. Territories will close their doors, in a time when these programs are needed the most - during and immediately following a period of high unemployment. State revenues are not available to bridge this funding gap since State coffers are being drained by the provision of minimal welfare and social services benefits to the unemployed and their families.

If I may, I would like to provide you with the results of a survey conducted by NASADAD on the status of State alcohol and drug abuse services systems. In the survey of the NASADAD membership, each State agency director was asked to provide a narrative description of any significant changes in the delivery of prevention and/or treatment services over the past year. State Directors were then asked to offer projections on future State (not Federal) resources. A brief State-by-State summary of the comments made in response to both of these questions is attached for your information.

In general, the comments made by the State agency directors reflect the uniqueness of the States and their service needs. Many of the States have increased their expenditures for prevention programs, a change which appears to be related to the ADM block grant requirement that 20 percent of the ADM block grant dollars be allocated for prevention, while in other States the Directors have independently decided to increase prevention services using State monies. In many States (eleven) the capacity to support treatment services declined in FY 1983; even though the perceived need in those States had increased due to economic conditions. In several States, there has been a change in the type of treatment services provided, with less chronic and/or institutional care and more early intervention type care.

Regarding FY 1984 State monies for alcohol and drug abuse services, the majority of States expressed hope that they would be able to maintain their current level of services for at least part of the Fiscal Year, only seven States indicated that they expected to receive funding increases in FY 1984. In these instances, the program increases seem to be related to projected alcohol tax increases, to commitments related to drunk driving programming and/or to the expansion of prevention programs. Ten States indicated that they expect to suffer significant reductions in funding in FY 1984.

Of greater importantce, is the fact that over 94 percent of the States responding to the NASADAD survey reported that an unmet need for treatment and prevention services exists within their State. Thus, even though the State may be able to maintain current services levels, it is not enough - there are still thousands of individuals who need and could benefit from some type of prevention or treatment services.

NASADAD is not only concerned about the President's budget request for the ADM Block Grant, but also the proposal to transfer administrative responsibility for the program to the Office of the Assistant Secretary of Health. Since it's authorization in FY 1982, the ADM block grant program has been administered by the Alcohol, Drug Abuse and Mental Health Administration. Prior to FY 1982, the alcohol and drug abuse project and formula grant programs were administered by NIAAA and NIDA. In both cases, the alcohol and drug grant programs were administered by program personnel in the Federal agency which had the most interest and knowledge regarding the problems of alcoholism and drug abuse and the services systems developed by the States in conjunction with the Federal government to respond to these illnesses. It does not make sense for responsibility for these programs to be transferred from the agency and personnel who have historically taken responsibility for the Federal role in alcoholism and drug abuse and to the Office of the Assistant Secretary of Health for the sake of convenience. It is not convenient for the States.

NIAAA and NIDA Appropriations Request

NASADAD wishes to express its support for the key leadership role which both NIAAA and NIDA continue to play at the Federal level. The Institutes have significantly revised their programmatic activities over the past two years and currently focus most of their efforts on alcohol and drug abuse research, in addition to a small research training program, continued data collection efforts and information dissemination. NASADAD applauds the Institutes' efforts to continually disseminate important research findings relevant to alcohol and drug abuse prevention and treatment services and encourages expansion of their technical assistance activities, to State, local and private organizations. The Administration's request for a continued, significant increase in the scope and capabilities of the NIAAA and NIDA research programs on these serious public health problems and the accompanying increase in the requested funding levels is also supported by NASADAD. The Federal investment in research, may yet reach a level commensurate with the burden of these illnesses on the American people.

Lack of Support for NIAAA and NIDA Clinical Training Efforts

NASADAD is particularly concerned that the NIAAA and NIDA clinical training efforts were eliminated in the FY 1983 appropriations process. We feel that just as the NIMH clinical training program was continued, similarly the NIAAA and NIDA clinical training programs should continue to receive support from members of Congress. The national alcohol and drug abuse training systems represented over a decade of coordinated effort by the Federal government, State alcohol and drug abuse authorities and local program personnel. NIDA's training system consisted in its major components of the National Drug Abuse Center, five Regional Support Centers, grants to practically all States and Territories for a State Training Support Program (STSP) and various other national efforts such as the Career Development Center and Management Internship Programs. In addition, diverse training programs were developed to provide an opportunity for paraprofessionals, members of minority groups and former addicts to develop better skills for services delivery and upward career movement. NIAAA had a similar system with a National Center for Alcohol Education and State Manpower and Development Programs (SMDP) in practically all the States. The Administration, in its request to eliminate the clinical training program, expressed the belief that there already existed an adequate pool of alcohol and drug abuse program personnel who have no further need for training programs aimed at improving services delivery, that non-Federal entities, i.e. the States, will continue to fund these programs. It seems particularly unsettling that at a time when unemployment has soared to levels rarely seen in this century, that the Federal Government does not continue to support an already existing training network which only requires a minor financial contribution from the Federal Government.

NASADAD requests that members of the Subcommittee re-evaluate their decision to eliminate funding for the NIAAA and NIDA clinical training programs. An appropriation of at least $5 million for each Institute in the form of Grants to the States for revitalization of the Statewide training networks should assist State efforts to repair the training network which has been severely crippled by the Federal government's elimination of funding support.

In closing, I encourage Subcommittee members to carefully review the following table, which documents the decline of Federal support for alcohol and drug abuse services programs administered by ADAMHA, NIDA and NIAAA since FY 1980. During the 1970's the Statewide services systems made great strides in its efforts to reduce and prevent alcoholism and drug abuse among our children, friends and colleagues. In recent years, however, these services systems have made little progress since Federal funding support was reduced by almost half. Please reconsider your level of support for these programs and assist the States in their efforts to expand their efforts to treat and prevent alcoholism and drug abuse.

Thank you.

($ in millions)

	FY 1980	FY 1981	FY 1982	FY 1983 (pre-jobs bill)	FY 1983 (post-jobs bill)
NIAAA & NIDA project and formula grants	$332.5	$264	--	--	
Alcohol and drug portion of ADM block grant	--	--	$223.9	$222.8	$237.8

ATTACHMENTS

Changes in Status of Services Systems in FY 1983 *

ALABAMA:	Treatment: reduced dollars for inpatient & outpatient services. Prevention: doubled dollars and services
ALASKA:	No major changes - under Block Grant continued programs funded by Feds.
ARIZONA:	Alcohol: more early intervention & less chronic care. Drug: expanding methadone maintenance & registering prevention service clients.
ARKANSAS:	Need to expand outpatient & residential alcohol treatment by 80%. Need education on cocaine. Need more attention to DWI & other alcohol related arrests; need more residential drug treatment for youth.
CALIFORNIA:	Are cutting State Operations Staff by 50% (200 to 100 persons), but treatment and prevention are OK.
COLORADO:	DWI evaluation/referral & treatment was transferred from highway office to SAA.
CONNECTICUT:	Active movement to more social setting detoxification; also active in areas of Parent Youth Professional Conferences, DWI Task Force, & shelter/alcohol services for homeless.

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* From NASADAD survey of membership conducted March 1983. Please note this is a brief summary of a much more extensive narrative provided by the States.

DELAWARE:	No major changes due to overlapping and carry over dollars.
FLORIDA:	More group counseling (& less individual counseling); some cuts in client services.
HAWAII:	Treatment programs are struggling to stay open.
ILLINOIS:	Alcohol: focus is on services in community settings rather than in State facilities. Drug: treatment capacity has been reduced due to funding cuts and a decision to increase the slot reimbursement rate to bring it closer to actual costs; have increased support for prevention programs.
INDIANA:	FY 83 dollars up 20% over FY 82 due to use of overlapping funding dollars and State dedicated tax dollars (passed in 1981); expanded all services.
IOWA:	Not much change, although some increase in prevention services.
KENTUCKY:	Replaced grant mechanism with a fee for service system. Increased emphasis on primary prevention.
LOUISIANA:	New DWI legislation effective 1/1/83, but do not yet know its impact on service demand.
MAINE:	New premium law on alcoholic beverages resulted in increased dedicated revenues for alcohol services and mandated interdepartmental cooperation. Have increased levels of both treatment and prevention including both services to institutionalized substance abusers and prevention directed to younger earlier stage drinkers.
MARYLAND:	Block Grant led to increased dollars for prevention. Also have implemented Statewide EAP.
MASSACHUSETTS:	Use Block Grant process to cut poor performing programs and fund improved programs more responsive to needs, e.g., for minorities & Hispanics. Used overlap dollars to extend services over time; Block Grant is a grand idea and preferable to direct Federal funding of local programs.
MICHIGAN:	Substance abuse programs & staff have been cut. Client waiting lists are up; more clients are unemployed.
MINNESOTA:	Have experienced funding cutbacks, especially for public clients (e.g., in medical assistance), now send clients to State hospitals.
MISSISSIPPI:	Some cuts in funding.
MISSOURI:	Adopted comprehensive services model & service area planning/resource allocation concept; transition from State hospitals to community based programs and services.
MONTANA:	Have maintained services at level prior to Block Grant funding.
NEVADA:	Using newly available alcohol excise tax monies earmarked for substance abuse services. Civil Protective Custody and Detoxification Services have been expended in some parts of the State. Due to the Block Grant requirement some programs have refocused their activities from treatment to prevention, resulting in a decrease in the number of treatment slots available. Due to the economic recession, Federal funding cutbacks and shrinking alternative funding sources, many alcohol and drug treatment and prevention programs are operating at extremely critical financial levels.
NEW JERSEY:	Due to funding cutbacks some programs have been reduced in size or closed. However, two small new programs have been opened to serve financially and medically indigent women.
NEW MEXICO:	Over past year treatment service needs increased 35% and prevention service needs increased 50%.
NEW YORK:	Drug: Lost 32% Federal dollars in transition to Block Grant therefore have fewer dollars at a time of increasing need; looking to alternative financing through private health insurance, EAPs, etc. Alcohol: The past year has been a sig-

nificant one for alcoholism services. New legislation related to drunk driving has resulted in the availability of fine money as a match for State administered funds on a 50/50 basis. The new Governor, Mario M. Cuomo, in his State of the State Message announced his intent to introduce and strongly support legislation mandating insurance coverage for alcoholism services. Governor Cuomo also highlighted employee assistance programs and prevention services as priorities for his administration.

NORTH CAROLINA:	Funding has remained relatively stable although it has not kept pace with inflation.
NORTH DAKOTA:	Became more active in prevention programming & hired a State Prevention Coordinator. (2)
OHIO:	Drug: Lost Federal dollars in Block Grant, Title XIX & XX reductions & also State unemployment & deficits leading to State deficits leading to State dollar reductions; therefore have consolidated & merged programs, combined alcohol & drug programs; developed more EAPs, decreased services provided, length of treatment & number of clients served; have wider range of prevention services. Alcohol: increases in private hospital based programs & youth prevention programs.
OKLAHOMA:	More concentration on treatment services for youth & adolescents & on prevention services.
OREGON:	Major change has been to support services on a slot funding basis. Also closed the alcohol & drug ward at Oregon State Hospital & moved intensive services to a nonhospital setting.
PENNSYLVANIA:	Used forward funding of grantees to ease 25% Federal funding cut; made 15% cut in period ending 6/83; stable 7/83 to 6/84, & project 10% additional cut in 7/84 to 6/85.
RHODE ISLAND:	Need has increased due to unemployment & DWI referrals; waiting lists are longer, but have fewer dollars available to meet the needs.
SOUTH CAROLINA:	Due to revenue shortfalls State FY 83 monies were reduced by 9%, but programs were not reduced; used Block Grant monies to expand prevention services and programs.
TENNESSEE:	Two significant changes: (1) notable increase in prevention funding plus targetting to areas of Fetal Alcohol Syndrome early intervention with high risk youth, & teacher training; (2) shift of detoxification & intensive residential services from institutional to community based programs.
TEXAS:	Drug: Major expansion of prevention services especially for at risk youth; also decrease in treatment services (6% since FY 82 & 11% since FY 81).
UTAH:	Significant increase in funding for prevention programs; also implemented a Public Inebriate Program including $1.5 million in earmarked monies from alcohol tax increases.
VERMONT:	Doubled State support for prevention activities. Reduced support for some treatment programs due to Block Grant cut.
VIRGINIA:	Support community based programs, citizen involvement, & interface between treatment & criminal justice systems.
WASHINGTON:	Experienced major cuts in FY 83 (e.g., 37% in drug outpatient services. Also major cuts in education, prevention, training & project grants). Block grant mechanism did not have a major impact although did expend some dollars differently.
WEST VIRGINIA:	State Supreme Court ruled that incarceration of chronic alcoholic for public intoxication is illegal & State must provide appropriate care. State & community behavioral health centers reallocated dollars to provide 24 hour screening, medical referral & shelter care.
WYOMING:	With State dollar increase of about 25% added residential treatment services.

Projections for State Monies in FY 1984

ALABAMA:	Hope for stable funding in FY 1984; do not expect to obtain requested increase.
ALASKA:	In FY 1984 expect 2½ million cut in State monies (16%) and will have to eliminate programs.
ARIZONA:	Expect significant reductions in FY 1984 State dollars (7 to 17%).
ARKANSAS:	Expect 7% increase for treatment to cover inflation costs. Are no general revenue State dollars for prevention services.
CALIFORNIA:	Expect stable Federal and State dollars for local programs, but don't know of county dollar level.
COLORADO:	In FY 1984, expect a maintenance level budget.
CONNECTICUT:	Expect at least stable funding plus 5.8% increase for community grants, and if tax bill passes, could receive $1.5 million.
DELAWARE:	In FY 1984 will reduce number of programs (but costs not due to dollars); expect major dollar problems in FY 1985.
DISTRICT OF COLUMBIA:	Have requested a major funding increase, but don't know whether it will be granted.
FLORIDA:	Some overall cuts in alcohol services, although more dollars for DWI & residential youth alcohol treatment; expect some increases in drug abuse services.
HAWAII:	Expect a slight decrease in State monies in FY 1984.
IDAHO:	Expect a decrease in State monies in FY 1984 of $300,000, but will try to reduce the impact of this cut in services through faster utilization of Block Grant monies; crunch will come in late 1984 or 1985.
ILLINOIS:	Alcohol: expect some funding cuts in FY 1984. Drug: in FY 1984 the budget will probably remain at about the current reduced level.
INDIANA:	Expect FY 1984 budget increase of 13%; will expand court alcohol and drug services programs by 50% in 2 years; priorities are youths residential treatment and youth prevention and early intervention.
IOWA:	Future is difficult to project; probably will be stable although could be some reductions, or if dedicated tax is passed, some increases.
KENTUCKY:	Expect status quo for FY 1984 State service funding.
LOUISIANA:	Expect budget cut of approximately 15% & further reorganization & consolidation of clinical facilities to cut costs.
MAINE:	Some new monies may be authorized, but they may be offset by declining alcohol sales and premium revenues.
MARYLAND:	Expect stable funding with exception of increase in outpatient services related to comprehensive DWI program.
MASSACHUSETTS:	Expect at least stable funding & possibly some increases. (Alcohol agency); hoping for stable funding (Drug agency).
MICHIGAN:	Hope for stable funding levels, with increased State taxes, insurance dollars, DWI fees, etc.
MINNESOTA:	Hope for stable funding.
MISSOURI:	Hope to work with General Assembly to generate resources required to meet needs.
MONTANA:	Expect funding to remain stable (have earmarked alcohol tax dollars going to counties).

NEBRASKA:	Expect no increase in State dollars; problems will occur in FYs 85 & 86 once carryover funds are depleted (programs may have to be cut 20 to 30%).
NEVADA:	State General Fund appropriations over the period FY 1983 - FY 1985 have been cut substantially.
NEW HAMPSHIRE:	If the initial budget is adopted services will be cut, but if alternative funding measures pass then services could be increased.
NEW JERSEY:	Hope to maintain current funding level and support existing programs.
NEW YORK:	Alcohol: Expect continuation of current level of State support. Drug: Proposed State budget projects stable State funding but cannot make up Federal funding cuts concurrent with Block Grant implementation therefore are experiencing cuts at a time of expanding needs.
NORTH CAROLINA:	In FY 83-84 expect stable funding but will transfer dollars from institutions to communities for alcohol services.
NORTH DAKOTA:	Don't know, but hope for stable funding in FY 1984.
OHIO:	Drug: Hope to obtain maintenance level of funding, including more State dollars to make up for loss of Federal dollars.
OKLAHOMA:	Due to declining tax revenues (oil glut) expect cuts of about 6% in State support.
OREGON:	Expect to maintain current level of services & funding in FY 1984.
PENNSYLVANIA:	Hope for stable funding in FY 84.
RHODE ISLAND:	Expect some cuts in State dollars that will lead to service cuts at a time when needs are increasing.
SOUTH CAROLINA:	Future funding appears stable, although State & local revenues are most questionable.
TENNESSEE:	Anticipate stable funding in FY 1984.
TEXAS:	Federal funds will be reduced by 28% in FY 1984, but the State is considering major funding increases (e.g., from current level of $210,000 to request of $10,704,690). Budget may decrease slightly; however, if public inebriate and/or DWI legislation is passed, additional State funds would be made available.
UTAH:	Hope for stable funding for treatment, plus $2 million increase for prevention.
VERMONT:	Expect to be able to maintain services at current levels.
VIRGINIA:	Expect budget increase of 10 to 15% in FY 1984.
WASHINGTON:	In FY 1984 expect major State dollar increases & restoration to higher 1982 level. Expect State prevention dollars to double from $850,000 to 1,700,000) and drug outpatient dollars to be restored.
WEST VIRGINIA:	Anticipate major State dollar increase ($2.7 million) for shelters & residential treatment (see Supreme Court ruling - item #6) plus expansion of substance abuse prevention & other services.
WISCONSIN:	Expect continuing decrease in State monies & services due to $2 billion budget deficit.
WYOMING:	Have biennial budget & anticipate 9% inflation increase in FY 1984; don't know about FY 85 (State dollar availability is related to uranium & oil prices).

STATEMENT OF RICHARD PRUSS, PRESIDENT, THERAPEUTIC COMMUNITIES OF AMERICA

Senator PROXMIRE. Our next witness is Richard Pruss, president of the Therapeutic Communities of America. Mr. Pruss, you are a very patient witness. We apologize for the late hour, but I think you understand, we have many witnesses.

Mr. PRUSS. I certainly do.

Mr. PRUSS. Thank you very much for this opportunity. Therapeutic Communities of America is a 300-member national organization of private, not-for-profit, residential drug-free treatment programs active in 47 States. The primary goal of our programs is permanent abstinence from drugs.

As I talk to you, our agencies are serving thousands of men and women who are teenagers, business people, athletes, tradespeople, small time drug dealers, musicians, drifters, artists, burglars, graduate students, car thieves, and office workers. In other words, they come to us from everywhere, and from every social and economic level, every educational background, every realm of brilliant accomplishment and drab failure, but all of them are now working at one thing, learning to live without drugs.

Everyone today has been talking a lot about appropriations and figures and statistics and facts, but there are times when they obscure something even more important: faces, personalities, human beings. We will be talking about waiting lists, but I want to be sure that no one overlooks the fact that there are people who are waiting.

Therapeutic Communities of America believes that drug abuse is a national problem which requires a Federal response.

The drug abuse problem will only yield to massive, sustained, three-part effort: sound enforcement, sound prevention, and sound treatment. To move on one or two fronts and not all three dooms the effort to failure. The current administration's response, however, has been inadequate at best. I would like to take a moment to review what has been done on each of those fronts to date.

Law enforcement, although not part of the ADM block grant, must be included in any discussion of the substance abuse problem in our country. The President has increased efforts to intercept drugs being smuggled into the country. He has made more funds available to do so, and we support that effort, and would like to see it further intensified and expanded. Current law enforcement efforts are insufficient in responding to the diversion of pharmaceutical products that can be abused, while poly-drug abuse is a major problem among our youth.

Education and prevention are of paramount importance. Long before programs were funded for prevention services, our treatment agencies provided trained speakers for schools, churches, and community organizations. Much of what can be done in prevention can and is being done at little cost. Two major forces have played a role in the education/prevention effort recently, and deserve extensive praise.

The first is the parents' movement. The National Federation of Parents for Drug-Free Youth has been at the forefront in educating families throughout America about the substance abuse problem and how it can be dealt with in the home and in the community by concerned parents who love their children and are willing to say "no."

The other is the First Lady, and I hasten to add, not to be confused with the actions of the administration. Mrs. Reagan, through her efforts, has focused the public's attention on the problem of drug abuse and the role of the family, more than any other single person in our country today.

Her message, as important as it is, however, can best be responded to by the middle and upper classes, where families are more intact than among the lower socioeconomic class, where basic survival takes so much time and energy, and families are frequently headed by one parent. For many, therefore, funded drug abuse prevention programs in schools and community centers are the only hope, but the administration has reduced their funding substantially.

Reductions in funding for those programs lead to a greater number of young people who end up in need of treatment. In a roundabout way, so does the heightened awareness of the drug abuse problem that has been accomplished by the successful efforts of parents' organizations. Parents are more apt to be aware of their children's need for treatment when they are better educated about drug abuse.

I might point out that each untreated abuser acts as an infector, spreading the disease of drug abuse among friends and acquaintences, and it is in the area of treatment services that the administration has made its most savage cuts, abandoning its commitment to the youth of America. When the block grant was first imposed, drug treatment programs were operating at 100 percent of their contractual capacity. The figures reported by the National Institute of Drug Abuse were confirmed by the data our national consortium collected.

But the Federal share of funding necessary to maintain these essential services was not maintained. On the contrary, the block grant formula imposed sudden and devastating funding reductions which amounted to a full third of the Federal support once provided by NIDA. Today, long waiting lists to enter treatment exist in almost every program throughout the country.

The original base of support in 1980 for drug abuse programing was $201 million. That includes prevention services and treatment services, all of the funds provided by the Federal Government. With the situation today, we can now expect $134 million in fiscal 1984.

Senator PROXMIRE. What was that first year? $201 million?

Mr. PRUSS. 1980. Fiscal year 1980.

If, as we respectfully request today, the subcommittee recommended an appropriation up to the full authorization level, we would then receive $158 million for drug abuse prevention and treatment. But that doesn't represent extravagance; it would still be a full 20 percent below the level of funding in fiscal year 1980, and I am not taking into account any aspect of inflation. Law enforcement and community-inspired prevention efforts cannot do the job alone.

Treatment programs are needed for those of our children who have already become victims. We can and should try to prevent any disease, but we can't let those who already have it go untreated, infect others, destroy families and themselves. These citizens, too, deserve our attention and are entitled to it. Programs should not be denied funds that were meager at best. We are asking that the subcommittee recommend and support an appropriation for the ADM block grant which is equal to the full congressional authorization.

Thank you.

Senator PROXMIRE. Thank you, Mr. Pruss, very much. The anecdotal material you have on page 3, for example, is very moving, the kind of thing that I think that is very effective with many of us. You talk about young people, desperate, burned out, staking everything on a last chance, and coming in for help and having to be told there is a waiting list, "Come back later." In some cases, they commit suicide, in other cases they just drift back into the hopeless situation.

Mr. PRUSS. Generally, behavior deteriorates terribly after somebody is turned away from a service program.

Senator PROXMIRE. That's a matter of funding.

Mr. PRUSS. The waiting lists that are created are a matter of funding.

Senator PROXMIRE. Turn away. The fact that you have turn away as big as you do.

Mr. PRUSS. Oh, absolutely. We are programs that—I think the expressionis—we don't "cream." Virtually anybody who comes in and wants placement in a program is accepted for a minimal amount of time while evaluations are done. We may find other, more appropriate means of treatment, but we will not turn anybody away because of how long they have been abusing drugs or because of——

Senator PROXMIRE. You turn them away because you simply don't have the facilities to take care of them.

Mr. PRUSS. That's correct.

Senator PROXMIRE. Could you give me some notion of what proportion you can accept, and what proportion you cannot because of inadequate funding?

Mr. PRUSS. Well, at this point, my own program has a— we are at 106 percent. I run a program in New York which is a 500-bed residential program. We are at 106 percent of our capacity.

Senator PROXMIRE. I see.

Mr. PRUSS. We accept beyond the capacity. We currently have a 2-week—generally it takes 2 weeks from the time somebody applies for the program until they get in. Waiting lists and drug abuse programs are very difficult to put together. People don't wait. The other things happen. They continue to use drugs. What we do is we ask people to call back each day, and if there's an available slot, we put them in.

Senator PROXMIRE. Thank you very much. A fine statement, and very helpful.

Mr. PRUSS. Thank you, sir.

[The statement follows:]

STATEMENT OF RICHARD PRUSS

My name is Richard Pruss and I am President of Therapeutic Communities of America, the 300 member national organization of drug-free residential treatment programs serving 15,000 men and women in 47 states and Canada.

I am grateful for the opportunity to represent them here today. Our basic request is simple. We are asking that the Sub-committee recommend and support an appropriation for the Fiscal 1984 Alcohol, Drug Abuse and Mental Health Block Grant which is equal to the full Congressional authorization, $532,000,000.

Our justification for this request can be briefly stated:we cannot deliver even marginally adequate service to all those who need our help unless we have the funding and we are now under severe pressure because funding has been so drastically cut in recent years. Here are the essential facts:

When the Block Grant was initiated two years ago, drug prevention and treatment programs were all operating at 100 per cent of capacity. The figures, reported by the National Institute on Drug Abuse, were amply confirmed by the data our national consortium collects.

But, the Federal share of the funding necessary to maintain these essential services were not maintained. On the contrary, the Block Grant Formula imposed sudden and devastating funding reductions which, as we have now determined, amounted to 33 per cent, a full third of the Federal support once provided by NIDA.

The original base of support was $201 million for drug abuse prevention and treatment programs. What is the situation today? We can now expect only $142 million in Fiscal 1984 for these services--$134 million in Block Grant money plus another $8 million from the new jobs legislation.

If, as we respectfully request, the Sub-committee recommends an appropriation up to the full authorization level $532 million, we would then receive $158 million for drug abuse prevention and treatment services. But, that does not represent extravagance either; it would still be a full 20 per cent below the level of funding in FY 1980-81.

Is there any reason to suppose that the crippling cuts in Federal support were somehow warranted by a decline in the need to prevent and treat drug abuse? Was there some dramatic setback for the illicit drug industry, some sudden falloff in the demand for its poisonous products? Not at all, although the Administration's ruthless slashes in NIDA's budget have also forced the agency to cut back on collection of drug abuse data, our own information, gathered nationwide, shows that the demands for treatment services are greater than ever. We are still at or above capacity. We all have lengthy waiting lists.

Let's take a closer look. Not long ago, the Columbia Broadcasting System visited my home agency, Samaritan Village in New York City, to talk with a few of our clients for a nationally televised report on what the funding cuts have meant.

Every one of these young people, desperate and burnt-out staking everything on a last chance, had approached us voluntarily in recent months. Every one had to be told that there was a waiting list, that there was no room for them immediately. What happened?

One youth squandered five weeks and $12,000 on a cocaine orgy, then tried to kill himself by plunging into the Hudson River. Rescued and hospitalized, he was finally able to enter our program. A young woman, equally depressed by what she felt was rejection, was admitted to a psychiatric hospital--and reached us later. Another youth--let me remind you that he, too, had sought voluntary admission returned to the streets and was arrested after several robberies. He was subsequently probated to us, after a totally unnecessary encounter with the overburdened criminal justice system.

There are more than a dozen other cases, but I hope my point is clear. Cutting funds for drug treatment has meant cutting off desperate human beings from hope. We are doing all we can to sustain services, but the reality is that for the many small programs that make up the bulk of TCA membership, there are only two choices: retrench or close. And when they shut down, even the last, tenuous hope offered by a waiting list vanishes.

In New York State, the impact of the Block Grants cuts on all drug programs amounted to $16 million, half of it in the prevention programs for school children that are a critical component of our total service.

No there has been no recession for the drug dealers. The indicators of that grim industry all signal prosperity. But, have the nation's bleak economic conditions had any measurable effect on substance abuse treatment programs? There is no question about it. In the State of Michigan, according to its Director of Substance Abuse Services, "more people than ever are seeking treatment for an alcohol or other drug program--and the majority of them are unemployed. Furthermore, waiting lists for these programs have been rising for the past year. It is worth quoting this official's comments on the situation:

"While unfortunate, a fact that we must face is that the conditions of a poor economy and high unemployment are the same conditions which lead to increases in the need for substance abuse services. To further cut back on services at this point would be devastating."

I have attached a copy of the news article from which I'm quoting. We take with utmost seriousness this warning that further cuts in substance abuse funding would be devastating. And, I need not remind the Sub-committee that inflation is imposing its own cruel cuts in the funding supply regardless of what the Administration's budget recommendations may be. Unless we get fresh help, and get it in the coming fiscal year, many of our programs are going to be permanently crippled.

Before I conclude, I want to call the Sub-committee's attention to a particularly strange irony. While the Reagan Administration has been savaging drug treatment services, Mrs. Nancy Reagan has been developing a national reputation as an advocate for some of these same programs. We do not question her sincerity or her concern. We do wish they also extended to drug abusers and families outside the financially serene surroundings of the upper middle class; in planning her itineraries, Mrs. Reagan seems most comfortable there.

In this case, actions speak more eloquently than words. We are respectfully aware that this Sub-committee has the power to act, directly and decisively, to help _all_ young people who are sincerely trying to help themselves.

STATEMENT OF DR. EDWARD J. CARELS, VICE PRESIDENT COMMUNICATIONS, COMPREHENSIVE CARE CORP.

Senator PROXMIRE. Our next witness is Dr. Edward Carels, vice president communications, Comprehensive Care Corp.

Dr. Carels, happy to have you here, sir.

Dr. CARELS. Thank you for the opportunity to speak to you this morning, Senator. Comprehensive Care Corp. is the Nation's largest private provider of alcoholism and drug-related treatment services. We treat approximately 40,000 patients per year.

Knowing of your concerns about where is the money going, and the questions that you have asked in the past, I would like to ask a question, too.

If you consider that alcoholism and alcohol abuse costs society in excess of $82.6 billion each year, and if there are an estimated 14 million alcoholics and problem drinkers in this country—and that number is growing by 400,000 each year—and if you consider that treatment is cost effective, as many have amply demonstrated, and if alcoholism contributes to 10 percent of the deaths in this country, and if alcoholism causes or aggravates more than 30 other diseases, and if alcohol abuse contributes significantly to all forms of crime in this country—and I might add anecdotally my own house was robbed yesterday, and the thieves, according to the police, are a ring of drug addicts in my neighborhood—I might also add that I have been held up at gunpoint on several occasions in the streets of Chicago, not Milwaukee—if alcohol is——

Senator PROXMIRE. Why not move to our State? [Laughter.]

Dr. CARELS. If alcohol is among the five most heavily advertised products in America, leading to widespread use and abuse, and if alcohol abuse contributes to a massive number of other social welfare problems, including child abuse, spouse abuse, mental retardation, and increased welfare payments—then why does this Nation spend less than four-tenths of 1 percent of its total health care bill treating the actual disease of alcoholism? Interestingly, America spends more money on bottled water, diet drinks, bicycles, and running shoes.

I am not without addressing a solution——

Senator PROXMIRE. When you say——

[Laughter.]

Senator PROXMIRE [continuing]. Running shoes, you are on dangerous ground here. [Laughter.]

Dr. CARELS. We are not oblivious to the financial realities, however. With Federal spending for medicare and medicaid projected to rise to $87 billion in 1984, we are aware of the Congress' commitment to maintain the solvency of these health care programs for 30 million medicare and 22 million medicaid beneficiaries. Revisions in payment methods, deductibles, changes in eligibility offer only a partial solution, I believe. New sources of revenue need to be explored.

One new source, it seems to me, would be to double the Federal excise tax on alcohol beverages. Since alcohol abuse accounts for 10 percent of this Nation's death toll and a sizable patient load in our community and psychiatric hospitals, a modest tax increase is a small price to pay for salvaging human lives.

Fundamentally, this tax increase would be a user tax. Nearly one-third of our population abstains from alcohol, and half of all the alcohol beverages sold in America are consumed by only 11 percent of the adult population. And the taxes on those beverages have not been raised in 32 years.

Knowing also of your concerns about research, I have a few comments here. While we believe that basic research and biological studies are vital to the understanding of these diseases, we urge that the psychosocial and economic aspects of these diseases be given equal attention. Some suggested areas for research are: why employers resist covering their employees for alcohol—let alone drug—problems in group health insurance policies, especially when ultimately they bear the costs of these diseases in terms of lost production, excessive accidents on the job, and health care expenditures for alcohol-related problems. It is interesting to note that only 37 percent of full-time private sector workers in America have any insurance coverage at all for alcohol abuse or alcoholism. I might add that generally speaking, from my review of the research, I think we know too much about the effects of drugs and alcohol on rats, and not enough on how to get sick people who need help into some kind of service.

I think another area of research would be why only 15 percent of this Nation's alcoholics and drug addicts receive formal treatment, and what can be done about it.

Another area might be why do people use drugs in the first place.

A last area I would like to mention is that of health planning. The certificate of need process has become a method of discrimination in some parts of the country, so far as drug abuse and alcoholism is concerned. In New York City, for example, it takes 3 years to open an alcohol program, and yet the State's own health care plan says that there is a need for 55 percent more beds for treatment in that State. We recommend the health care planning process be more streamlined.

Thank you very much.

Senator PROXMIRE. Well, thank you very much. You suggested doubling the excise tax on alcohol. You said taxes were not raised in 32 years? The last raise was in 1951?

Dr. CARELS. That's correct.

Senator PROXMIRE. That's remarkable. I wonder why they raised that? That was, maybe, the Korean War—it was a matter of financing that, or something. OK. I am surprised that that was the last year there was any raise at all.

Now, our excise tax on alcohol—I should know this, but can you tell me, is that an absolute figure per quart or per fifth, or is it related to the price of the alcohol?

Dr. CARELS. I really don't know the answer to that question.

Mr. Dirks. Per gallon.

Dr. Carels. Per gallon, is it.

Senator Proxmire. Per gallon. I thought, Harley, you would know that. [Laughter.]

Thank you very, very much. Fine statement.

Dr. Carels. Thank you.

Senator Proxmire. We appreciate it.

[The statement follows:]

STATEMENT OF DR. EDWARD J. CARELS

THANK YOU FOR THIS OPPORTUNITY TO DISCUSS FEDERAL FUNDING PRIORITIES IN THE HEALTH CARE FIELD.

I AM DR. EDWARD CARELS, VICE PRESIDENT OF COMMUNICATIONS FOR COMPREHENSIVE CARE CORPORATION, A NATIONWIDE HEALTH CARE MANAGEMENT COMPANY. WE ARE THE NATION'S LARGEST PRIVATE PROVIDER OF ALCOHOLISM AND RELATED DRUG TREATMENT SERVICES THROUGH OUR HOSPITALS, FREESTANDING PROGRAMS AND CAREUNITS WITHIN COMMUNITY HOSPITALS. ADDITIONALLY, WE OPERATE PSYCHIATRIC SERVICES, EMPLOYEE ASSISTANCE PROGRAMS FOR GOVERNMENT AND PRIVATE INDUSTRY, REHABILITATION SERVICES, EATING DISORDERS UNITS, COMMUNITY COUNSELING AND REFERRAL SERVICES AND A PUBLICATIONS COMPANY.

AS THIS NATION ENTERS AN ERA OF HEALTH CARE RATIONING, WE HAVE DETECTED A DISTURBING TREND. THE STIGMATIZED ILLNESSES OF ALCOHOL AND DRUG DEPENDENCIES AND ABUSE AND MENTAL ILLNESS ARE MORE SEVERELY IMPACTED THAN OTHER DISEASES, DESPITE THEIR PREVALENCE AND DEADLY CONSEQUENCES.

IN A RECENT GALLUP POLL, FOUR OUT OF FIVE AMERICANS SAID ALCOHOL ABUSE IS A MAJOR NATIONAL PROBLEM, AND ONE OUT OF THREE ADMITTED THAT DRINKING HAD BEEN A CAUSE OF TROUBLE IN THEIR FAMILIES. THE NATIONAL HOUSEHOLD SURVEY ON DRUG ABUSE SHOWS THAT ONE THIRD OF THE POPULATION, AGE 12 AND OLDER, HAVE USED MARIJUANA, COCAINE, OR OTHER PSYCHOTHERAPEUTIC DRUGS. ONE IN FIVE HAVE USED THESE DRUGS WITHIN THE LAST YEAR. THE SURVEY ALSO SHOWED THAT 2.3 MILLION YOUNG ADULTS USE MARIJUANA DAILY. IN ADDITION TO AMERICANS DEPENDENT UPON OR ABUSING ALCOHOL AND OTHER DRUGS, THERE IS ESTIMATED 10 TO 15 PERCENT OF POPULATION SUFFERING FROM MENTAL DISORDERS SEVERE ENOUGH TO REQUIRE TREATMENT. ALCOHOL, DRUG ABUSE AND MENTAL ILLNESS COST THIS NATION SOME $177.3 BILLION ANNUALLY IN LOST PRODUCTION, DEATH, MEDICAL CARE, CRIME AND SOCIAL WELFARE.

RESEARCH STUDIES HAVE PROVED AGAIN AND AGAIN THAT TREATMENT FOR THESE DISEASES USUALLY RESULTS IN IMPROVEMENT AND RECOVERY, AND SAVES MONEY. A RECENT REPORT FROM THE OFFICE OF TECHNOLOGY ASSESSMENT SAID "THE COSTS OF NOT PROVIDING TREATMENT (FOR ALCOHOLISM) MAY BE GREATER THAN THE COSTS OF PROVIDING SUCH TREATMENT." THE REPORT ADDED THAT AVAILABLE COST BENEFIT ANALYSES "OF ALCOHOLISM TREATMENT SERVICES INDICATE SIGNIFICANT REDUCTIONS IN MEDICAL CARE UTILIZATION AND TIME LOST DUE TO ILLNESS COMPARED TO THE COSTS OF TREATMENT." YET, WHEN HEALTH CARE BUDGETS TIGHTEN, THESE DISEASES ARE DISCRIMINATED AGAINST.

THE BLOCK GRANT AMOUNT ALLOCATED FOR COMMUNITY TREATMENT PROGRAMS FOR ALCOHOLISM, DRUG ABUSE AND MENTAL ILLNESS REMAINS AT $439 MILLION, THE SAME LEVEL AS THE PREVIOUS FISCAL YEAR, WHICH IN REAL DOLLARS AMOUNTS TO A DECREASE. WE URGE AN INCREASE IN FUNDING TO KEEP UP WITH INFLATION AND TO AID THESE PROGRAMS IN HELPING THE LARGE NUMBERS OF UNEMPLOYED PEOPLE SEEKING ASSISTANCE.

MORE SUBTLE FUNDING CUTBACKS AFFECTING ALCOHOLISM TREATMENT ARE OCCURRING UNDER MEDICARE. IN INTERPRETING REVISED MEDICARE GUIDELINES FOR ALCOHOLISM TREATMENT, SOME PEER REVIEW ORGANIZATIONS HAVE BLOCKED THE TREATMENT AND REHABILITATION OF ELDERLY ALCOHOLICS. IF A MEDICAL DIRECTOR ADHERED TO THE SIGNS AND SYMPTOMS CITED BY SOME PEER REVIEW CRITERIA, THE PATIENT WOULD HAVE TO HAVE BEEN ADMITTED TO AN INTENSIVE MEDICAL CARE UNIT, RATHER THAN AN ALCOHOLISM REHABILITATION PROGRAM. THESE UNREASONABLE INTERPRETATIONS OF MEDICARE GUIDELINES REPRESENT BAD MEDICINE AND FAULTY ECONOMIC REASONING. IT IS CONSERVATIVELY ESTIMATED THAT 20 PERCENT OF ALL HOSPITALIZED PATIENTS ARE THERE FOR ALCOHOL-RELATED CAUSES, INCLUDING PANCREATITIS, HEART MUSCLE DISORDERS, LIVER DYSFUNCTION, ESOPHAGEAL CANCER AND INJURIES. IT MAKES BOTH COMMON AND ECONOMIC SENSE TO TREAT THE CAUSE OF THESE PROBLEMS -- ALCOHOLISM AND ALCOHOL ABUSE --RATHER THAN JUST

THE COMPLICATIONS. CONTINUED FEDERAL FUNDING OF PEER REVIEWS WHICH ENCOURAGE THE OPPOSITE APPROACH WILL BE VERY COSTLY TO GOVERNMENT.

UNDER MEDICAID, THERE IS NO STATED POLICY ON ALCOHOLISM TREATMENT. STATES DETERMINE WHETHER ALCOHOLISM IS COVERED OR NOT AND MANY DO NOT. IRONICALLY, THE POOR OFTEN TURN TO DRUGS AND ALCOHOL DURING ECONOMIC DOWNTURNS.

WHILE WE ARE QUESTIONING THE TREATMENT PRIORITIES OF MEDICARE AND MEDICAID, WE ARE NOT OBLIVIOUS TO THE FINANCIAL REALITIES. WITH FEDERAL SPENDING FOR MEDICARE AND MEDICAID PROJECTED TO RISE TO $87.7 BILLION IN 1984, WE ARE AWARE OF CONGRESS' COMMITMENT TO MAINTAIN THE SOLVENCY OF THESE HEALTH CARE PROGRAMS FOR 30 MILLION MEDICARE AND 22 MILLION MEDICAID BENEFICIARIES. REVISIONS IN PAYMENT METHODS, DEDUCTIBLES, CHANGES IN ELIGIBILITY OFFER ONLY A PARTIAL SOLUTION. NEW SOURCES OF REVENUE NEED TO BE EXPLORED. ONE NEW SOURCE WOULD BE TO DOUBLE THE FEDERAL EXCISE TAX ON ALCOHOL BEVERAGES. SINCE ALCOHOL ABUSE ACCOUNTS FOR 10 PERCENT OF THIS NATION'S DEATH TOLL, AND SIZEABLE PATIENT LOAD IN OUR COMMUNITY AND PSYCHIATRIC HOSPITALS, A MODEST TAX INCREASE IS A SMALL PRICE TO PAY FOR SALVAGING HUMAN LIVES. FUNDAMENTALLY, THE TAX INCREASE WOULD BE A USER TAX. NEARLY ONE-THIRD OF OUR POPULATION ABSTAINS FROM ALCOHOL. HALF OF ALL ALCOHOL BEVERAGES SOLD ARE CONSUMED BY ONLY 11 PERCENT OF THE ADULT POPULATION. AND THE TAXES ON THOSE BEVERAGES HAVE NOT BEEN RAISED IN 32 YEARS.

IN REVIEWING THE SUGGESTED APPROPRIATIONS FOR ALCOHOL, DRUG ABUSE AND MENTAL HEALTH ADMINISTRATION, WE ARE DELIGHTED TO SEE AN INCREASE IN RESEARCH APPROPRIATIONS. MORE THAN PROVIDING CARE FOR SOME 35,000 PATIENTS ANNUALLY, COMPCARE IS COMMITTED TO RESEARCH. WE HAVE PRIVATELY FUNDED RESEARCH IN THE AREAS OF PRESENTING PROBLEMS OF ADOLESCENTS IN SUBSTANCE ABUSE PROGRAMS, MEDICAL COMPLICATIONS OF ALCOHOLISM, POLYDRUG ABUSE, TREATMENT EFFECTIVENESS, INSURANCE EXCLUSIONS, BARRIERS TO TREATMENT, AND

RELATIONSHIP OF ALCOHOLISM TO HEREDITY FACTORS. WHILE WE BELIEVE THAT BASIC RESEARCH AND BIOLOGICAL STUDIES ARE VITAL TO THE UNDERSTANDING OF THESE DISEASES, WE URGE THAT THE PSYCHO-SOCIAL AND ECONOMIC ASPECTS OF THESE DISEASES BE GIVEN EQUAL ATTENTION. SOME SUGGESTED AREAS OF RESEARCH ARE:

1. WHY EMPLOYERS RESIST COVERING THEIR EMPLOYEES FOR ALCOHOL LET ALONE DRUG PROBLEMS IN GROUP POLICIES, ESPECIALLY WHEN THEY ULTIMATELY PAY FOR SUCH A LARGE PORTION OF ALCOHOL ABUSE'S COST TO SOCIETY IN TERMS OF LOST PRODUCTION, EXCESSIVE ACCIDENTS AND HEALTH CARE EXPENDITURES. ONLY 37.9 PERCENT OF FULL-TIME PRIVATE SECTOR WORKERS HAVE ANY HEALTH INSURANCE THAT COVERS TREATMENT FOR ALCOHOLISM OR ALCOHOL ABUSE.
2. THE INCIDENCE OF FETAL ALCOHOL SYNDROME AMONG NEWBORNS OF RECOVERING WOMEN.
3. WHY ONLY 15 PERCENT OF THIS NATION'S ALCOHOLICS RECEIVE FORMAL TREATMENT AND WHAT CAN BE DONE ABOUT IT.
4. COMPARISONS OF PRESENTING PROBLEMS OF INPATIENTS AND OUTPATIENTS.
5. POLYDRUG ABUSE AND ITS EFFECTS ON TREATMENT.
6. FAMILY FACTORS INFLUENCING AMAS (PATIENTS WHO LEAVE TREATMENT AGAINST MEDICAL ADVISE.)

HEALTH PLANNING IS ANOTHER CONTROVERSIAL AREA UNDER THIS SUBCOMMITTEE'S PURVIEW. IN OUR EXPERIENCE, THE NATIONAL HEALTH PLANNING AND RESOURCES DEVELOPMENT ACT THWARTS ITS OWN GOALS OF EQUAL ACCESS TO QUALITY HEALTH CARE AT A REASONABLE PRICE. WHEN 85 PERCENT OF THIS NATION'S PROBLEM DRINKERS ARE NOT RECEIVING ANY FORMAL TREATMENT AND WHEN 75 PERCENT OF THE MENTALLY ILL ARE NOT BEING SEEN BY MENTAL HEALTH PROFESSIONALS, THERE IS AN OBVIOUS NEED FOR OUR SPECIALIZED TREATMENT PROGRAMS. BUT THE CERTIFICATE OF NEED PROCESS DELAYS THE OPENING OF OUR PROGRAMS FROM SIX MONTHS TO THREE

YEARS. THE LAYERS OF BUREAUCRACY WE MUST CONVINCE OF THESE SELF-EVIDENT NEEDS ONLY RAISES HEALTH CARE COSTS. EACH CON APPLICATION COSTS US $35,000. HEALTH PLANNING, IF IT IS TO CONTINUE, NEEDS TO BE STREAMLINED. WE OPPOSE CONTINUED FUNDING FOR HSAS AND RECOMMEND THAT THE CON PROCESS BECOME A STATE OPTION RATHER THAN MANDATED PROGRAM AND THAT MILLION DOLLAR CON THRESHOLDS BE ADOPTED. WE UNDERSTAND THAT ONE-QUARTER OF ALL CON PROJECTS INVOLVE EXPENDITURES OF $1 MILLION OR MORE. IT IS THOSE PROJECTS WHICH NEED SCRUTINY, RATHER THAN LOW COST PROJECTS SUCH AS OURS WHICH CONVERT EMPTY HOSPITAL BEDS TO HELP SOLVE THE SEVERE COMMUNITY PROBLEMS OF CHEMICAL DEPENDENCY AND MENTAL ILLNESS.

AS YOU CONSIDER APPROPRIATIONS FOR HEALTH FUNCTIONS, WE WOULD ASK YOU TO CONSIDER THE FOLLOWING:

1. IF ALCOHOLISM AND ALCOHOL ABUSE COST SOCIETY IN EXCESS OF $82.6 BILLION IN 1983 DOLLARS, AND
2. IF THERE ARE AN ESTIMATED 14.6 MILLION ALCOHOLICS AND PROBLEM DRINKERS IN THIS COUNTRY, AND THAT NUMBER IS GROWING BY SOME 400,000 EACH YEAR, AND
3. IF TREATMENT IS COST-EFFECTIVE AS HAS BEEN AMPLY DEMONSTRATED, AND
4. IF ALCOHOLISM IS A CHRONIC, PROGRESSIVE AND OFTEN FATAL DISEASE, WHICH COUPLED WITH ALCOHOL ABUSE CONTRIBUTES TO 10 PERCENT OF THIS NATION'S DEATH TOLL, AND
5. IF ALCOHOLISM CAUSES OR AGGRAVATES MORE THAN 30 OTHER DISEASES, AND
6. IF ALCOHOL ABUSE CONTRIBUTES SIGNIFICANTLY TO ALL FORMS OF CRIME IN THIS COUNTRY, AND
7. IF ALCOHOL IS AMONG THE FIVE MOST HEAVILY ADVERTISED PRODUCTS IN AMERICA, LEADING TO WIDESPREAD USE AND ABUSE, AND
8. IF ALCOHOL ABUSE CONTRIBUTES TO A MASSIVE NUMBER OF SOCIAL WELFARE PROBLEMS, INCLUDING SPOUSE

BEATING, CHILD ABUSE, DIVORCE, MENTAL RETARDATION AMONG CHILDREN OF ALCOHOL DEPENDENT MOTHERS, INCREASED WELFARE PAYMENTS,

THEN

WHY DOES THIS NATION SPEND LESS THAN FOUR TENTHS OF A PERCENT OF ITS TOTAL HEALTH BILL ON TREATING THE ACTUAL DISEASE OF ALCOHOLISM? AMERICA SPENDS MORE MONEY ON BOTTLED WATER, DIET DRINKS, BICYCLES AND RUNNING SHOES.

STATEMENT OF RODOLFO BALLI SANCHEZ, NATIONAL EXECUTIVE DIRECTOR, NATIONAL COALITION OF HISPANIC MENTAL HEALTH AND HUMAN SERVICE ORGANIZATIONS

PREPARED STATEMENT

Senator Proxmire. Our final witness gets the prize for the most patient. You have been here a long time. Mr. Rodolfo Balli Sanchez, national executive director of the National Coalition of Hispanic Mental Health and Human Service Organizations.

[The statement follows:]

STATEMENT OF RODOLFO BALLI SANCHEZ

I am Rodolfo Sanchez, the national executive director of COSSMHO. Our organization is the only national Hispanic health and human services network linking local agencies, research centers, and professionals working with Mexican American, Puerto Rican, Cuban, and Latino communities. COSSMHO affiliates are active in more than 220 urban and rural areas in 30 states, the District of Columbia, and the Commonwealth of Puerto Rico.

The programs and funding levels of the Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA) have a direct impact on the day-to-day work, as well as the future course, of a significant part of COSSMHO's national network. This includes community mental health centers, drug and alcohol treatment programs, multiservice agencies, research and training programs, and mental health professionals whose service populations are predominately high-risk groups in Hispanic communities, such as children, youth, women, families, and the elderly.

In your deliberations on ADAMHA's budget for fiscal 1984, we urge that you consider and support the major Hispanic priorities which are the subject of this statement. In these priority areas, other ethnic and racial minorities in this country share similar concerns.

Data Collection, Analysis, and Reporting

We wish to underscore the importance to Hispanics of a strong ADAMHA role in this area. Current mental health, drug and alcohol abuse statistics on Hispanics are severely limited or non-existent. If we are not visible in the statistics, we will remain invisible -- or at least, marginal -- in policy, planning, and programming. We recommend the following steps:

-- ADAMHA Institutes are cooperating in the Hispanic Health and Nutrition Examination Survey, the first large-scale endeavor to gather basic information on the health status of this country's Hispanic population which numbers some 14.6 million persons on the U.S. mainland, according to the 1980 census, and which is projected to become our country's largest ethnic minority in the imminent future. Continued support for this cooperation by the ADAMHA Institutes, and for their analysis and reporting on the data when such become available, is essential.

-- As long as ADAMHA administers the alcohol, drug abuse, and mental health (ADM) block grant program, concerted efforts should be made to encourage and assist states to gather and share data on Hispanics served through this program. Under ADM service programs previously administered by the agency's Institutes, some limited data on admissions and other items were available, but are no longer required under the new program.

ADAMHA also should closely monitor and report on the impact of the block grant program on Hispanic services at state and local levels. As you know, there were expressed concerns about how Hispanic providers, clients, and at-risk populations would fare under this new approach, and this continues to be a prime focus for oversight.

-- Surveys and other data gathering efforts which are ongoing within the ADAMHA Institutes should be implemented with a focus on Hispanics and distinct Hispanic subgroups. It is important that our specialized needs and circumstances be taken into account when such efforts are planned and that the sample size be adequate to allow us to appear in the data that are gathered.

Research

COSSMHO supports increased funding for ADAMHA research. Along with attention given to recent biomedical advances and their potential for deepening our understanding of various diseases, we wish to cite the continuing importance of building an Hispanic ADM research capacity across mental health relevant disciplines.

The base of scientific knowledge applicable to Hispanics and to distinct Hispanic subgroups is still at a developing stage in terms of demographics, epidemiology, differentials of culture, class, and language that significantly influence treatment outcomes and prevention approaches, and treatment assessment.

Strengthening and expanding this base is crucial in dispelling stereotypes that have dominated the field historically and still persist, in deepening our understanding of the complex interplay of factors that precipitate or aggravate ADM disorders among particular disadvantaged Hispanic groups, and in providing the guidance and the tools to help treat or prevent disorders among such groups.

An important part of this Hispanic research effort is continuing support for information transfer to assure that Hispanic relevant ADM advances are transmitted and applied at the level of planning and practice by both Hispanics and non-Hispanics. In this regard, we at COSSMHO are keenly aware of the high level of expressed need by both Hispanics and non-Hispanics alike for information and help in improving services and programs for Hispanics in need.

There are several areas where further investigations hold promise. Some of these, for illustrative purposes, are: epidemiological studies to document the need for specific mental health services, to identify the incidence and prevalence of specific disorders among Hispanic populations in relation to other well-defined groups; factors influencing services utilization; the interplay between health and behavior; culturally appropriate diagnosis and treatment of specific disorders; extent and use of alternative helping resources and systems; Hispanic family dynamics and mental health implications in such areas as child rearing, the extended family supports, etc.; and what treatment modalities work best with particular Hispanic client groups and why. Cross-cultural and cross-ethnic research should also be encouraged.

The Hispanic research capacity described here should be a clear priority throughout the Institutes. We urge that NIDA and NIAAA support such a priority similar to that already underway at NIMH. Given the reports from Hispanic providers and community leaders, both NIDA and NIAAA should direct more attention and resources to problems and solutions applicable to Hispanic youth and to the growing number of Hispanic women needing and seeking help.

In helping achieve a stronger Hispanic ADM research capacity, we support a strong ADAMHA role in providing technical assistance to help increase the number of competitive research applications submitted by Hispanic investigators.

Prevention

Increased prevention activity throughout ADAMHA is a top priority for Hispanics, given the size and projected increase of our population and the swelling numbers of infants, children, and youth, as well our many families (both single and dual parent) at risk because of lower levels of income, education, opportunity, and access to health and mental health care. Clearly, prevention research and prevention initiatives targeted on specific high-risk groups hold enormous potential, in human and social benefits, for our communities.

Our concern here is not only to urge allocation of prevention resources to Hispanic concerns, but also that strategies for utilizing these resources be developed according to the varying conditions and circumstances of distinct Hispanic groups. Given the pioneering nature of this field, it is also important that resources be used creatively to stimulate studies and activities on Hispanic-specific needs and solutions, as well as how these compare or differ from other groups. Here again, it is crucial that ADAMHA reach out to improve our competitiveness in the grants and contracts process and to increase our involvement in the planning and implementation of specific initiatives.

Training

Increasing the pool of Hispanic mental health service providers and researchers continues to be a national priority and will remain so for the foreseeable future.

There are far too few Hispanics in psychiatry, psychology, social work, and psychiatric nursing to come anywhere near meeting projected needs for culturally sensitive services and care. There are far too few to provide anywhere near the consultation services increasingly required by government, the voluntary sector, and various institutions in order to upgrade their outreach and involvement with our communities.

In the mental health professions Hispanics account for little more than 0.5% of the work force. Among graduate students in these professions, Hispanics comprise only 2% or less, with the exception of social work where Hispanics make up about 4% of those enrolled. The President's Commission on Mental Health took special note of the shortage in psychiatry and psychology. It noted that fewer than 2% of all psychiatrists in this country are black and the percent of Hispanic psychiatrists is even lower. It also cited a survey by the American Psychological Association estimating that of all doctoral-level health service providers in psychology, 0.4% are Hispanic.

A correlate of Hispanic underrepresentation in all disciplines relevant to mental health is the fact that not enough Hispanic specialists are available to work with children, youth, families, and the elderly who comprise the majority of the Hispanic disadvantaged groups at high-risk for mental and emotional disorders. Our experience at COSSMHO further attests to this need. We are bombarded by requests from Hispanics -- and especially from non-Hispanics -- to help identify Hispanic professionals skilled in working with families, with youth in school, with delinquent youth, with youth in detention, with children having difficulties in school, with pregnant teenagers and teen parents, with isolated elderly. These requests come not only from states where Hispanics have traditionally clustered, but more so from other urban and rural areas where the Hispanic presence is becoming more pronounced each day, such as New England, the Midwest, the prairie states, the Northwest.

The results of the shortage of Hispanic personnel overall, as well as in specialties highly pertinent to our identified high-risk populations, are costly. At the level of service, many in need are unserved, underserved, or inappropriately served -- an affliction to the people and a waste of valuable, scarce resources. In research, the volume and quality of studies focusing on Hispanics are constrained, and the flow of information essential to better understanding and better practice is impeded. Efforts to attract and motivate our youth to pursue mental health careers are also hampered by too few role models.

The reasons for Hispanic underrepresentation in mental health professions are complex and are part of a larger problem -- the rapid and progressive attrition of Hispanics from the educational system from one grade to the next. Solutions must start early, and mechanisms must be in place to assist individuals to move across the continuum that stretches from interest to commitment to study to training to practice. In this effort, responsibility should be shared -- on the part of parents and counselors, communities, states, schools, colleges and universities, professional associations, the voluntary sector, foundations, and the Federal Government.

But there is no doubt that federal leadership in training has been the key factor in boosting Hispanic and other minority participation in mental health professions over the past decade. Given our growing Hispanic population, the need for financial supports to help our young people enter and complete training, and the still limited number of Hispanic professionals in practice and in the pipeline, now is not the time to slow this trend or reverse it.

Toward this end, we urge that increased funds be provided for clinical and research training, that a major portion of any increases be directed toward Hispanics and other minorities, and that the funds be allocated in a reasonable balance among the various mental health relevant disciplines. Further, programs proven to be successful, such as the Minority Fellowship Program, should be strengthened so that support can be provided to more of the reported qualified applicants.

On behalf of COSSMHO and the Hispanic communities our members serve, I thank the subcommittee for its consideration of this statement in its deliberations on FY 1984 recommended funding for ADAMHA.

Mr. SANCHEZ. Good morning, Senator.

Senator PROXMIRE. Mr. Sanchez. We are happy to have you.

Mr. SANCHEZ. I made sure that I was not going to leave Wisconsin out, so I have brought that along.

Senator PROXMIRE. Yes; I notice you have got the Wisconsin Conference of Hispanic Families.

Mr. SANCHEZ. We are planning another one this year——

Senator PROXMIRE. Good.

Mr. SANCHEZ [continuing]. This fall. Already, I spoke to the people in Wisconsin yesterday.

Thank you very much. I don't mind waiting. I will try to be as brief as I can. Mr. Chairman, I am here on behalf of COSSMHO. Our organization is the only national Hispanic organization of its kind in the health and human service sector, including alcohol, drug abuse, mental health concerns.

You already know in my full testimony that we represent over 250 community-based, direct service agencies in over 227 cities and 32 States, and that Wisconsin happens to be one of them.

We have submitted written testimony to the subcommittee. For the sake of brevity, I wish to highlight key points of concern to our membership and the Hispanic community they serve. You have already heard Dr. Mayer, the Administrator of ADAMHA, presenting the key aspects of the President's budget request for fiscal 1984. We support the proposed increases in research funding and continued funding for research training, but because of the pressing personnel need of our communities, we urge continued support for clinical training.

Permit me now to summarize major Hispanic priorities in relation to the proposed budget for ADAMHA. One, in the area of data collection, a strong role for ADAMHA is needed here. Current mental health, drug, and alcohol abuse statistics on Hispanics and on specific Hispanic groups are severely limited. If we are not visible in the statistics, we will remain invisible in policy, planning, and programing.

The ADAMHA institutes are now cooperating in the Hispanic HANES. We urge continued support for this cooperation, and for adequate funds to insure analysis and reporting on the data when such become available. Also, as long as ADAMHA administers the block grant programs for alcohol, drug, and mental health, it should closely monitor and report on the impact of this program on Hispanic services at State and local levels.

Two, research. We note a continuing emphasis on biomedical research. We recognize the rationale and anticipate benefits to all. But for the Hispanic communities, other research in psychological and social science fields should also be encouraged to explore significant cultural and linguistic differences affecting access to services, diagnosis, and treatment, affecting treatment modalities and utilization of services.

In the area of prevention, this area is of the highest importance to us, given the rapid growth of the Hispanic population and the youthfulness of our people. Nearly 50 percent of our entire Hispanic population is under the age of 20, and our many families, youth and children at risk. Dr. Mayer noted that mental health, drug, and alcohol abuse programs are estimated to have cost our country $106 billion in 1977. We Hispanics know that cost is still high in several instances. We continue to be told by community leaders that inhalant abuse and PCP use are major problems for our young people in the Southwest and the West. We continue to hear that alcoholism is the No. 1 cause of death among Mexican Americans in Los Angeles County.

Clearly, it is important for our communities and for the country of which we are a growing part that we invest in educating and training our Hispanic youth about positive mental health, about the dangers of alcohol and drug abuse. In order to do this, specialized, culturally sensitive and culturally specific approaches are needed.

Both prevention and treatment are immensely aided by ADAMHA support for multinational, interdisciplinary conferences which involve Hispanics from the United States and professionals from Mexico and the Caribbean. These types of conferences, most recently, have included the U.S.-Mexico Border Symposium on Alcohol, Drug Abuse, and Mental Health, and the Caribbean Conference on Health and Mental Health Linkages, of which COSSMHO has been a part. We urge continued support for such efforts, because of the flow of people from these regions and the need for us to share knowledge and experience about how to treat and prevent problems that arise from this migration.

Training. Increasing the pool of Hispanic mental health service providers, and research continues to be a major priority. Thus, we urge increased support for clinical and research training. Our needs in training are longstanding and still pressing. This was particularly highlighted again at our Wisconsin Conference on the Hispanic Family held last October in Milwaukee.

In the mental health professions—psychiatry, psychology, social work, and psychiatric nursing— Hispanics account for little more than 0.5 percent of the work force. Among graduate students in these professions, Hispanics comprise only 2 percent or less, with the sole exception of social work, where the figure is about 4 percent.

In conclusion, sir, I wish to emphasize that our concern is not only for more dollars, but rather for better allocation of existing and new dollars to an at-risk population.

Last Friday, April 22, I met with Secretary Heckler. We discussed the need to address the Hispanic population, an at-risk population. She expressed deep awareness of and sensitivity to our concerns. I urge the subcommittee to provide her with the support that is needed to translate this concern into renewed action, not only in ADAMHA, but throughout the Department of Health and Human Services. I thank you, sir.

Senator PROXMIRE. Thank you very much, sir. The statistic that you gave on Los Angeles—Los Angeles County must have the largest number of Hispanic people of any county in the country; is that right?

Mr. SANCHEZ. Yes, it does. East Los Angeles alone has over 2 million Mexican-Americans. The State of California has 4,235,000, or 4,300,000 Mexican-Americans. In your State of Wisconsin, they estimate anywhere from 75,000 to 150,000 and very growing population. Within the next 10 years, the State of Wisconsin will probably triple in population, or quadruple.

Senator PROXMIRE. But the reason I brought California into it is because right now that is the heaviest single area, and the statistic you gave was that alcoholism is the No. 1 cause of death among youth——

Mr. SANCHEZ. Among the Mexican-American population in Los Angeles, as reported from the hospitals.

See, one of the problems that we have is we do not have data statistics. For the first time in the history of the United States, the Hispanic HANES are just taking place now, but the data will not be concluded by the National Center for Health Statistics until 1986.

Senator PROXMIRE. What period is this figure that you have given us, the alcoholism as a cause of death in Los Angeles?

Mr. SANCHEZ. OK. This was last year's report, given to me by——

Senator PROXMIRE. For 1982?

Mr. SANCHEZ. For 1982 and for 1981. For the past 2 or 3 years, this has been consistently the major cause of death.

Senator PROXMIRE. Is this a direct cause, because of the effect of alcohol on the system, that they die because of excessive consumption, or is it related to automobile accidents and that kind of thing—violence?

Mr. SANCHEZ. No; it's—of course, we have a great number of automobile accidents and death among our youth, a tremendous problem with alcoholism and drugs.

Senator PROXMIRE. Are you including that in this figure?

Mr. SANCHEZ. No; this is due to illness, in the hospitals.

Senator PROXMIRE. Illness. I see. Well, that's a tragic figure. It's one that I think very few people appreciate.

Mr. SANCHEZ. Well, we were shocked, sir. We did not realize, you see, and we are hoping that the committee will encourage all of HHS to continue to gather and monitor the States to provide this kind of data, because——

Senator PROXMIRE. Do you view alcohol as the principal drug problem, more important than any other?

Mr. SANCHEZ. I would say that it's touch and go. It depends. Alcoholism is a major problem in our adult as well as our youth, but I am very concerned about drugs, particularly inhalants and all other kinds of drugs, among our youth, sir. I mean, I—it's just——

Senator PROXMIRE. Well, I realize that both are very, very serious. I just wondered if you would say that alcohol is a greater problem than all the other drugs combined. Is that a fair statement or not?

Mr. SANCHEZ. I would say so. I would say that alcoholism is a major problem in this country, and particularly——

Senator PROXMIRE. I am talking about Hispanics.

Mr. Sanchez. I would say yes, because of the economic situation, the social environment, and—no offense, but also the socioeconomic and political. People feel rejected, they feel discriminated against, they are underemployed, have poor housing, they have a tremendous dropout rate—45 to 75 percent of our Hispanic youth are dropping out of school. I mean, they have horrible working conditions. You know, like in the——

Senator Proxmire. Let me just ask you one more question on it, because you have been very patient, and I realize the hour is late. But what prevention policy do you think would be most effective? And would you feel that prevention is more effective than treatment?

Mr. Sanchez. I would say that if we're not going to have the money for the Hispanic community—we have never had the money for treatment or services—then I place a high priority on prevention, if we are not going to have the money.

Senator Proxmire. What kind of prevention? Do you think a—older drinking age, or what?

Mr. Sanchez. I would say to start out with the youth, the little ones. I go around the country and I speak to the high school kids, and I would love to have the time and the funds to go into the junior highs. There is a program, in fact, in your State, Wisconsin, that's a tremendous model. It's by the Council of Spanish Speaking, I believe, in Milwaukee, and has a puppeteer, a puppet program, that they take, it's a drug program, and they take it to the kindergarten, first, second, and third graders, and through the puppeteer show they show the dangers of drug abuse, and it's the model program in your State of Wisconsin.

Senator Proxmire. Drug abuse and alcohol abuse.

Mr. Sanchez. For drug abuse.

Senator Proxmire. Drug abuse.

Mr. Sanchez. Yes.

Senator Proxmire. That's marvelous. Well, I am delighted to hear that.

Mr. Sanchez. Yes.

Senator Proxmire. Well, thank you very much, Mr. Sanchez.

Mr. Sanchez. Thank you very much, and I want to tell you I have always admired you for the Golden Fleece Award. You have never been wrong——

[Laughter.]

Mr. Sanchez. You have always been on target.

Senator Proxmire. Very good. Thank you. I appreciate that very much. Your statement has been included in the record, and other statements submitted for the hearing record on appropriations for the Alcohol, Drug Abuse, and Mental Health Administratrion will be included at this point.

[The statements follow:]

STATEMENT OF LUCILLE KELLEY, R.N., M.N., PRESIDENT, NATIONAL COUNCIL OF COMMUNITY MENTAL HEALTH CENTERS

Thank you Mr. Chairman for giving the National Council of Community Mental Health Centers the opportunity to present testimony on the FY 84 Labor-HHS Appropriations. The National Council of Community Mental Health Centers represents over 700 community mental health programs nationwide. Our constituents have a combined annual employment of 70,000 persons, and the aggregate operating budgets amount to $1.4 billion.

Community mental health programs provide a wide array of mental health services to people of all ages and disability groups. These programs are designed for short-term treatment with a major emphasis on outpatient and preventive services. Community mental health programs afford a large percentage of people an opportunity to remain in their community with family and friends at a lower cost than institutional care.

Last year CMHC's served approximately 3.5 million people, which is about one-third of the specialty mental health episodes in the United States. An increasing number of patients/clients being served in community mental health programs have serious mental illness, including schizophrenia and depression. These patients/clients account for over 20% of all admissions to CMHC's. Community mental health centers have significantly reduced admission rates to state institutions as compared with those areas without CMHC's.

Alcohol, Drug Abuse & Mental Health Block Grant

As you know, Mr. Chairman, the Alcohol, Drug Abuse and Mental Health categorical programs were consolidated into the ADM Block Grant as part of the Omnibus Reconciliation Act of 1981 (P.L. 97-35). The ADM Block Grant is essentially two block grants programs within one authority, with different requirements and provisions for substance abuse programs and mental health services. All mental health funds must be channeled through CMHC programs. These funds must be used to emphasize outpatient care to the chronically mentally ill, children, elderly and underserved populations. A CMHC must provide at least outpatient services, 24 hr. emergency services, day treatment or partial hospitalization, screening of patients being considered for admission to state mental hospitals, and consultation and education.

Prior to the implementation of the ADM Block Grant, in FY 81, alcohol, drug abuse and mental health programs were funded at a $638 million level. In FY 83, the current funding level is $469 million, which is a 26% reduction from the FY 81 level. In addition, when inflation is taken into account the actual reduction of funding for mental health services reaches over 40%. The erosion of Federal support for community mental health services has forced many community mental health programs throughout the country to lay-off personnel and reduce or eliminate services. In many instances, services that are generally the most cost-effective, such as consultation and education have had to be severely restricted because of budgetary constraints.

Although Federal support for community mental health services has shrunk over the last couple of years, the demand for mental health services has drastically increased. High unemployment has placed additional pressure on the mental health system. The mental health implications of unemployment have been well documented. For example Dr. Harvey Brenner, who has studied the impact of unemployment for many years, calculated that for each rise of 1% in the unemployment rate, 4.3% more men and 2.5% more women are admitted to state mental hospitals for the first time, 4.1% more commit suicide, and 1.9% more people die of stress-related diseases, such as heart disease, or from the effect of alcoholism and other physical ailments. Other studies have pointed out that emotional problems are not only peculiar to the unemployed individual but his/her family may also suffer from emotional difficulties.

The National Institute of Mental Health has examined five special programs established by community mental health centers in areas of unemployment which are designed to provide services to the unemployed and their families. These centers report a 10% increase in their total case load as a result of unemployment related problems. These centers report that 36% of the patients have marital problems; 27% report parent-child problems; 7% are cases of spouse abuse; 14% report cases of substance abuse; 6% show violent or suicidal behavior and 3% are child abuse cases. Our organization surveyed our members and we found that 62% of the centers responding indicated an increase in the proportion of patients with unemployment related problems during the past year. It is important to note that even if unemployment is reduced in the next year or so, studies have indicated that these stress related disorders will linger for several more years.

The individual who suffers from an unemployment related mental health problem is only one factor in the increased demand on community mental health programs. In addition, it is estimated that over 10 million Americans have lost health insurance coverage due to unemployment. Many of these persons do not have anyway to pay for needed health care services. Community mental health centers provide a cost-efficient setting for these persons to receive needed mental health services. For example, some unemployment related programs offered by CMHC's are as follows: Group therapy for unemployed workers; referral networks; stress management; family group therapy; placement counseling; outreach programs utilizing the media; and working with industry and labor unions to counsel those laid-off or about to be laid-off. These programs are generally low-cost and in the long run will prevent additional health and social costs including family break-ups, child and spouse abuse, violent behavior and institutionalization.

In addition to the increased demand caused by unemployment and the loss of health insurance coverage, there still remains segments of our population, including the elderly, children, and minorities, who are unable to obtain needed mental health services due to the lack of adequate resources to meet this need. Therefore, the demand for community mental health services will not diminish even after the high rate of unemployment is lowered.

Finally, the financial pressures on CMHC's to meet this escalating demand for mental health services comes from many sources. In addition to the erosion of ADM funds, Federal support for the Medicaid program and Title XX(Social Services) have also been curtailed. In response to the recent cutbacks in the Medicaid program, some states have had to reduce coverage of outpatient mental health services. Moreover, social services, a major base of support for community mental health programs, have also been severely limited. The end result of all these factors is an expanding demand for mental health services without adequate resources to meet this need.

We believe in order to meet the needs of those persons afflicted with mental and emotional disorders the FY 84 ADM Appropriation must at a minimum remain at the current services level of $469 million. However, the $469 million level would still fall $63 million below the FY 84 authorization level of $532 million.

Community Support Program

The Community Support Program is a small NIMH sponsored demonstration program which provides modest funding to help states develop a comprehensive community-based system for the care of the chronically mentally ill. States have used these grants to assess needs, identify and fill gaps in service and design and coordinate the range of services needed by chronically mentally ill persons in the community.

The results from Community Support Programs throughout the country have been very positive. In general, findings have shown that CSP's have reduced hospitalization by 50% for the chronically mentally ill population. These funds have stimulated states to invest state and local resources in the care of the chronically mentally ill. Finally, numerous innovative programs have been developed by the states in the areas of housing, employment, rehabilitation and case management.

The current (FY 83) appropriation for the CSP is $6 million. However, the Administration's FY 84 budget proposes to eliminate this program. We urge the Committee to continue the Community Support Program as a separate program apart from the ADM Block Grant. We also encourage the Committee to consider expanding the CSP Model and appropriating the necessary funds to allow for a children and youth mental health demonstration program.

On behalf of the National Council of Community Mental Health Centers we wish to thank you for giving us this opportunity to express our views on the FY 84 ADM and CSP Appropriations, and look forward to working with the Committee in its further deliberations on spending priorities for FY 84.

Statement of the National Association of State Mental Health Program Directors

The directors of the mental health programs of the 54 state and territorial governments address in this statement the way in which federal funds should be employed in developing adequate manpower for services to the mentally ill.

FEDERAL TRAINING DOLLARS SHOULD BE RESTORED AND RELATED TO STATE GOVERNMENTS

Over the past 15 years the state-government mental health commissioners have come before a number of congressional committees in support of a whole range of federal programs for the mentally disabled.

Today our concern is focused in one area: the problems related to mental health training and manpower development.

The time is upon us when the state-governments must urge that the state-government voice and the state-government role be enhanced in the development and utilization of mental health manpower appropriate to the public needs.

Psychiatrists, nurses, social workers, psychologists and mental health paraprofessionals should not exclusively be trained with federal dollars without relationship to the needs for specialized mental health services throughout the nation, and without relationship to the system most capable of judging public mental health manpower needs at both the community and hospital level, namely: state-government.

The 54 state and territorial governments expend each year on mental health services $6.7 billion dollars.

There are three phenomena connected with this effort that deserve special attention:

First... each year a greater-and-greater proportion of the above cited sum is devoted by the states to services for the mentally ill at the community level, a movement away from large hospital-based care. (In 12 states this year, the budgets for care of the mentally ill in the community are now larger than for care in state hospitals.)

Second...as the heavy swing to community treatment intensifies, the need compounds for specially-trained personnel.

Third...the federal government contributes only minimal support to the staggeringly difficult mental health training efforts of the 54 states government mental health agencies. (Only 20% of the FY 1983 NIMH mental health training budget is allocated to assist the states in meeting the enormous manpower task confronting them --- $4.1 million out of $20.09 million.)

In FY 1983 the Congress appropriated to the National Institute of Mental Health a sum of $20,093,000 for clinical training in the mental health professions with a clear directive to initiate a "new" program to address specialty manpower shortages, assist minority/disadvantaged students and to further expand the current State manpower development program.

The state mental health agencies appreciate the support Congress has provided to this program. In FY 1983 applications for funding under the State Manpower Development Program totaled $6,609,272 million ($3,400,806 non-competitive continuation grants to 21 states and $3,208,466 for 26 applications for competitive grant funding).

Due to the reduced level of FY 1983 appropriations for NIMH clinical training ($20,093,000) the State Manpower Development Program actually received $500,000 less than the previous year despite the number of new and renewal applications received.

Again the Administration budget request for zero funding for FY 1984 clinical training is, in the judgement of the state government mental health directors, not in the best interest of public mental health services.

Zero funding represents a $20 million cut in vital mental health training programs --- by far the deepest of which (20% of the total) will be felt by the state government mental health manpower development programs.

The cut in state government manpower training would be a critical blow in this era of (a) maldistribution of treatment personnel and (b) transition from "hospital-based" to "community" treatment programs. The state training effort is the most dynamic and most essential of new training concepts.

NASMHPD supports, at this time, an NIMH clinical training appropriation of $25,000,000 for FY 1984, and we ask that no less than $6 million of whatever amount is appropriated be allocated to "State Mental Health Manpower Development"

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COLLABORATION BETWEEN ACADEMIC INSTITUTIONS AND STATE GOVERNMENT ON MENTAL HEALTH MANPOWER TRAINING

A second and critical question that also needs to be addressed in mental health training is this-- what is the most effective way, with the highest degree of accountability, that the Congressionally appropriated money can be utilized?

The state-government mental health programs submit, that the needs for manpower in the public sectors (both community and hospitals) are so over-riding that the federal training funds in the mental health professions should only be allocated to educational institutions that demonstrate collaboration with the state government mental health agencies in the development of training programs designed to meet identified manpower needs within the state. Federal mental health training dollars should be utilized in the development of a mental health manpower training capacity in accordance with appropriate needs of mental health services in each state.

In recognition of the necessity to develop a strategy to address critical manpower problems within the states, the program guidelines for the "Mental Health Services Manpower Systems Development Program" (Catelog of Federal Domestic Assistance #13.244) have required "states" to demonstrate and show evidence of collaborations with "educational institutions" as a condition for receiving funds. We support this requirement which has added to the effectiveness and success of the program. (See Exhibit #1.)

However, to date similar guidelines requiring "educational institutions" to demonstrate evidence of collaboration with "state mental health agencies" as a condition to receiving federal grant funds have not been written into the guidelines for the minority/disadvantaged fellowship or shortage specialty grant programs.

One sided collaborative requirements does not make good public policy.

The state governments request that the Federal government move into a more active role in encouraging the educational institutions and the state mental health agencies to work together in identifying needs and developing plans and strategies to meet the manpower problems within the states.

This would be an appropriate role for the Federal Government and one that would be encouraged by the state government mental health agencies as a major step toward the development of all the factors that must be considered in establishing a comprehensive manpower plan and system.

It is in this area that the states need federal assistance. The Federal Government must now shift its emphasis from one of support for particular training programs to one of support for overall state manpower development plans. The leadership and responsibility for making a manpower program operational is clearly at the state level, but the federal government can provide assistance to the states in conceptualizing and implementing such comprehensive mental health manpower development programs in concert with the educational institutions within the state. As an example of how effective these collaborative relationships work, attached is a summary of the outcomes of a program in Maryland (see Exhibit #2).

The state-government mental health programs call upon Congress and the Federal Government to focus on new initiatives in training that will be responsive to the service delivery needs as determined by state and federal government in close coordination with the educational institutions.

In making appropriations for mental health manpower programs, the Congress should attach these directives to its dollars:

THE FEDERAL GOVERNMENT SHOULD:

1) develop an accelerated manpower development program focused on State and local manpower planning, with new forms of collaboration between educational insitutions and State and Local Governments.

2) revitilize its fiscal and philosophical support of basic training in the core mental health disciplines: psychiatry, psychology, social work and psychiatric nursing; re-emphasizing the vital role of the core professionals with expertise in the social and behavioral sciences, as the necessary underpinning of the mental health service delivery system, but with assurances that one objective of the training program will be curing the problem of mal-distribution of mental health manpower.

3) expand the range of experimental research and development activities in the sphere of basic mental health manpower development

4) proceed to support research and development on manpower issues in the sphere of primary care.

SUMMARY:

The state government mental health programs urge Congress to appropriate $25 million for clinical mental health training programs, providing such training programs are responsive to the service delivery needs of the nation. But, in the event of fiscal constraints first priority must be a continued federal emphasis on state MH manpower development programs.

We submit that one way that the nations's service delivery needs will be given maximum consideration and attention will be to begin to move the mental health training dollars in conformance with a comprehensive national and state mental health manpower plan.

STATEMENT OF RODOLFO BALLI SANCHEZ

I am Rodolfo Balli Sanchez, the national executive director of COSSMHO. Our organization is the only national Hispanic health and human services network linking local service agencies, research and training programs, and both service and research professionals working with Mexican American, Puerto Rican, Cuban, and Latino communities. Our affiliates are active in more than 220 urban and rural areas in 30 states, the District of Columbia, and the Commonwealth of Puerto Rico.

COSSMHO welcomes this opportunity to submit, for your consideration and for the record, this statement concerning the fiscal 1984 health and human services budget. This statement is in addition to our previous testimony on funding for ADAMHA and covers further areas of importance to our membership and the Hispanic communities they serve across the country.

The budget is a crucial force not only for meeting current gaps and inequities affecting Hispanic health and social functioning, but also for making a positive difference for our people's future, especially through targeting resources on Hispanic at-risk populations such as poor families, children, youth, and the elderly, and through expanding the emphasis on disease prevention and health promotion.

Hispanics have the highest birth and fertility rates in the U.S. Our rate of growth far exceeds the rates of other groups. According to the census, Hispanics increased 61% in the decade from 1970 to 1980. Even if our rate should decrease somewhat over the next 20 years, as some project, it will still outstrip other groups. Not only is our increase dramatic in states where we have traditionally settled (such as California, the Southwest, Illinois, New York, and Florida), but also in other regions (Northeast, Mid-Atlantic, Midwest, and the Pacific Northwest), a strong Hispanic presence is emerging.

Hispanics comprise our nation's most youthful population: nearly half of us are under age 20. Thus, as an investment in our country's future, a clear national commitment should be made now to help our young people shape healthy and productive lives, remain so as adults, and impart these benefits to their children.

Yet a significant number of Hispanic families, youth, and children fall into lower socio-economic brackets and are more likely than most other Americans to be at high risk for poorer health, serious illness, or disability. Both experience and the literature (most recently, the report of the National Institute of Medicine, Health and Behavior) confirm that poorer health status and its attendant risks are inextricably linked with social and economic disadvantage. In this regard, many Hispanics are indeed at hazard:

- One of every four Hispanic families is poor, more than double the number of other U.S. families. The greatest number are found among Mexican Americans in the Southwest, while the highest proportion are found among Puerto Rican and Latino groups in the Northeast. Hispanic families are larger on the average than non-Hispanic families. As family size increases, so does the likelihood of poverty: 41.5% of Hispanic families with seven or more members live in poverty.

- Hispanics fall substantially below non-Hispanics in educational attainment, a factor crucial to occupation, income, and access to health care. Only 42% of Hispanics age 25 and older have finished high school, while 69% of non-Hispanics have. Only 7% of Hispanics report having a college degree, while 17% of all others have. At the local level, Hispanic attrition from the educational system is truly alarming. Dropout rates for our youth are estimated to average 33%, while in cities such as New York, Chicago, and Los Angeles, it may run as high as 77%.

- Unemployment has always been higher for Hispanics and continues to run at over 14%. In 1982 it averaged 13.9% for Mexican Americans, 17.6% for Puerto Ricans, and 11.2% for Cubans. For all these groups, it is worse for women than for men. For our youth, it is as high as 50% in some communities.

- Concentration in inner cities, substandard housing, and overcrowding are more prevalent among Hispanics than other groups.

- In addition to problems faced in seeking and obtaining services and care because of cultural, language, and geographic barriers, cost is a major factor. According to the 1979 report to Congress by the Department of Health and Human

Services, the lowest levels of health insurance coverage under both private and public plans are among Hispanics, especially the poor. Recent findings to be incorporated into the Department's 1983 report to Congress indicate that Puerto Ricans and Cubans, along with blacks, have a non-coverage rate twice that of whites, but among Mexican-Americans the rate is 2½ times that of white non-Hispanics. Further, with regard to Medicaid coverage, proportionately twice as many blacks and three times as many Puerto Ricans have coverage compared to Mexican Americans.

We therefore urge your continued support for the following:

1. The Hispanic Health and Nutrition Examination Survey (Hispanic HANES). This study is being conducted by the National Center for Health Statistics and other HHS agencies are cooperating in various components. It will provide urgently needed baseline data on Hispanics with regard to illness, disability, need for treatment, nutritional habits, and patterns of growth and development. We urge the Department to give full backing to this effort and to ensure adequate funding to analyze, report, and widely disseminate the data which become available.

2. Improved Data Collection on Hispanics. Congress mandated this action by enacting P.L. 94-311, and continuing oversight is needed here. HHS agencies should utilize their ongoing surveys, as well as contractual studies, to gather and report data on Hispanics, but this is not widely occurring despite the evident need to know how best to target resources on Hispanics most at risk.

3. Oversight of Health Block Grants. Because of previous expressed concern about how Hispanics and other underserved populations would fare under this approach, it is vital that the Department work closely with the states to gather, share, and report data on the impact of health block grants, not only with regard to client accessibility to services, but also with regard to strengthening local and state networks of agencies and centers developed over the past decade to meet the specialized needs of Hispanics and other underserved groups.

4. Expanded Hispanic Participation in Health Promotion. Greater resources and more concentrated efforts should be made to apply what is known in the field of health promotion to populations at high risk for serious illness and disability. According to the National Institute of Medicine, as much as 50% of mortality from the ten leading causes of death among Americans can be attributed to lifestyle, i.e., to individual behavior which can be changed.

While health promotion is widely recognized as the key to future progress in reducing the burden and cost of illness and disability, Hispanic participation in this field has been negligible to date. COSSMHO is cooperating with the Department of Health and Human Services in a special project to address this situation. This project is the national health promotion training network in which the American Red Cross, the National Urban League, and the YMCA are also participating.

As part of this effort, COSSMHO conducted a national survey which found that Hispanic communities have a strong interest in health promotion but are limited by scant resources. Most cannot maintain ongoing programs, but provide only sporadic activities. Many communities with significant concentrations of Hispanics do not have access to a comprehensive set of health promotion resources. Where progress has occurred, partnership with the Federal Government has been a key factor: thus, the greatest number of programs we found were in areas where federal funding has figured prominently -- drug and alcohol abuse, nutrition, and hypertension. But in other areas ranked as top priorities by HHS -- smoking cessation, fitness and exercise, stress management, and safety -- there is almost no institutional activity geared toward Hispanics.

In light of the Hispanic population growth rate, the swelling numbers of Hispanic young people, and the weight of socio-economic risk factors imperilling many poor Hispanic families and children, we regard increased Hispanic participation in health promotion as a major priority. Factors of language and culture, which distinguish Hispanic groups from one another as well as from other U.S. population groups, require special strategies and approaches toward implementing effective health promotion programs among our people. Widely varying community resources and local public-private partnerships must also be considered.

COSSMHO is the only national Hispanic organization with a formally structured health promotion program, and we are urging a strong initiative to develop and implement a comprehensive, coordinated approach to health promotion for Hispanics, involving heightened awareness, education, and information among consumers and providers, local demonstrations mobilizing indigenous community support networks and resources, and collaborative efforts with business, industry, labor, schools, churches, civic groups, and voluntary interests. In mounting and sustaining such an action campaign, vigorous national leadership is a vital catalyst.

5. Improved Health of Hispanic Mothers and Infants. Hispanic women who become pregnant are much more likely to receive no care or late care, or to go fewer times for prenatal care. Hispanic mothers were four times more likely than non-Hispanic mothers to have received no prenatal care or to have initiated this care in the third trimester of pregnancy (13.1% vs. 3.3%). The figure for the

Hispanic mothers is 20% higher than for black non-Hispanic mothers (13.1% vs. 10.9%). Hispanic women who received prenatal care had the lowest median number of visits of the three groups (11.3 for whites, 10.7 for blacks, and 9.3 for Hispanics). Given that Hispanic women have the highest fertility of the three, the provision of timely prenatal care for Hispanic mothers continues to be a major priority.

6. Adolescent Pregnancy Prevention and Care. Overall, Hispanic mothers are younger than white non-Hispanic mothers, are more likely to have dropped out of school (usually by the sophomore year of high school), tend to receive late rather than early prenatal care, and have more babies with low birth weight. Educational attainment is lowest for Mexican American mothers (37% finished high school compared to 82.1% of white non-Hispanic mothers and 62% of black non-Hispanic mothers). The risk of low birth weight is relatively high for Puerto Rican babies (9% compared to 5.7% for whites).

Of Hispanic mothers, 19% were under age 20, compared to 12.1% for whites, and the highest proportion of Hispanic teenage births are for Mexican American women (20.1%) and Puerto Rican women (23.4%). Our cultural traditions and heritage which emphasize the centrality of the family place high importance on keeping and rearing our children.

Various studies indicate that Hispanic teen mothers or teenagers who become pregnant tend to be disadvantaged economically and educationally, to be at risk of repeat pregnancy, to live in a large household, to be less likely to use formal services and more likely to rely on family and informal supports. Models of service delivery to adults are not appropriate for this age group, and aggressive outreach and followup are crucial.

COSSMHO is fully supportive of the funding priority given to the Adolescent Family Life Demonstration Program, but we are concerned as to whether allocation of these funds is being effectively targeted on Hispanic and other minority populations well known to be at risk, as well as on Hispanic and other minority applicants best positioned to reach and serve this special teen population. We urge your review and oversight in this regard to ensure that this initiative of the President and the Department assists those most in need in the most effective, efficient manner.

7. Community and Migrant Health Centers. These centers provide health care to significant numbers of Hispanics, most of whom have no other available source of care. In many rural communities, they are the only available providers for miles. Community health centers report that Hispanics account for about 16% of

clients served, and in certain geographic areas, such as California, Texas, and New Mexico, the rate exceeds this national average. Under the migrant health center program, an estimated 60-65% of those served are Hispanics.

8. Health Research. We recognize our nation's leadership in biomedical research and the potential this holds for all Americans. We wish to note the importance of developing a base of scientific knowledge applicable to Hispanics and distinct Hispanic groups in terms of epidemiology, cultural and class differentials, and services access and utilization. We urge more collaborative medical and behavioral studies related to lifestyle as recommended by the National Institute of Medicine. These should include specific components related to Hispanics, minorities, and other at-risk groups.

9. Health Careers. A concentrated effort is needed, beginning early in the schools and at home, to recruit and encourage Hispanic young people to pursue health service and health research careers. Hispanic students are still far too few in various health professions schools: 3.1% of those enrolled in medicine; 2.3% in dentistry; 1.8% in optometry; 0.7% in pharmacy; 0.5% in psychiatry. In addition to supporting the various federal programs that provide minority health career training, we urge that those designed to recruit and motivate youth expand their focus from high school seniors to include those at lower grade levels. This will enable us to expand the pool of potential recruits and assist our youth to plan and prepare for successful careers.

10. Health Information for Consumers/Patients. COSSMHO wishes to commend the continuing outreach of the Food and Drug Administration's Office of Consumer Affairs to minority communities and to the newly established National Council on Patient Information and Education. COSSMHO works with the FDA Office through its Consumer Consortium and recognizes the importance of assisting individuals and families to exercise greater responsibility for good health and nutrition. Various studies indicate that physicians and family members are primary sources of health information among Hispanic populations.

11. Human Development Services. COSSMHO supports increased funding for Head Start which has proved to be most successful in aiding low-income children and parents, including many who are Hispanics.

We also wish to note that despite reductions in funds and staff, OHDS has made efforts to make its limited resources more accessible to more smaller grantees, for example, improving competitiveness through its coordinated grants program. We also support the emphasis given in various programs to reorient services and care to home and community settings, both of which accord well with Hispanic values and provide more assurance of assistance in a culturally sensitive environment. Targeting resources to improving self-sufficiency of our families and communities is a direction beneficial to Hispanics, enabling more of us to participate more fully in society and chart our own course.

STATEMENT OF F. JAY PEPPER, M.D., PAST PRESIDENT, MEDICAL SOCIETY OF ST. ELIZABETHS HOSPITAL

I would like [redacted] concerning the FY '84 Budget proposal for [redacted]

I am a past president of the Medical Society of Saint Elizabeths Hospital, an organization 45 years old and representing 500 Mental Health Professionals. Since I am no longer employed by the Hospital, the Society has asked me to provide an evaluation of the Hospital's 1984 fiscal allowance as proposed by the Administration. I would like to bring to your attention the highlights of that evaluation.

Budget

Saint Elizabeths Hospital continues to be the major resource in serving the nation's Capital's most desperate, most dangerous, most disabled, most deprived mentally ill. My evaluation finds that the proposed 1984 allowance has a number of major impediments to the Hospital in carrying out its responsibilities, to wit:

--The overall OMB proposal of $143,524,000 appears adequate, but the direct Federal appropriation is $62,744,000, leaving $70,780,000 to be collected from reimbursements, including "Reimbursement from the District of Columbia" of $68,653,000. Of that figure $14,000,000 comes from Medicaid, leaving the District of Columbia $54,000,000 to pay in FY '84. In FY "83, the District of Columbia paid $22-24,000,000 for SEH services and it is believed their FY '84 budget contains $29,000,000 for SEH services. The difference between $54,000,000 and $29,000,000 is $25,000,000. Where is this to come from?

Personnel Ceiling

--The FY '84 proposals calls for the largest personnel ceiling decrease in anyone's memory. To begin with, the change of full-time permanent positions from 3933 to 3650 is a decrease of about 7%. Moreover, in addition the Administration's Budget Proposal asks a further reduction of 182 positions through requiring the Hospital to alter its past prudent policy of having patient hirees and trainees exempt from personnel ceiling computations. This 182 is approximately 5% of the 3650, bringing the total potential cut, in a single year, of full-time permanent positions to 12%. This is in addition to reduction of the past three years.

Of more importance is the full-time equivalent (FTE) employment ceiling. Here the change is from 3960 to 3300. Again, the 182 must be counted, making for a real change of 3960 to 3118 (3300-182), a cut of about 20%. This is despite an increased admissions rate and despite the Hospital's need to remain JCAH accredited, to remain Medicare/Medicaid-eligible, to meet its court-ordered Dixon obligations, and--most importantly--to meet satisfactory standards of psychiatric care. Plaintiffs in the Dixon case have already asked that District Mental Health officials be found in contempt of court for not having the mandated services.

Recommendations

--I would therefore recommend:

I. That Saint Elizabeths Hospital personnel ceilings not be decreased and thus,

  A. The full-time permanent ceiling remain at 3933 and the full-time equivalent ceiling remain at 3960.

  B. The handicapped psychiatric patient hirees remain exempt from the ceiling computation.

C. Trainees remain exempt from the ceiling computation.

II. That Saint Elizabeths Hospital receive an indefinite Federal appropriation within the overall 1984 budget allowance. This is consistent with the budget submissions of the Hospital throughout the 1960s and 1970s and will not put the Hospital in a shortfall position, as has occurred to the District's D. C. General Hospital.

To accomplish I., B and C, I am under the impression that it is necessary that the budget languages specifically indicate that patient hirees and trainees be exempt from ceiling.

I think that there are several questions needing to be asked of the Administration's '84 Budget Proposal in order to continue quality care at Saint Elizabeths Hospital. If you believe I might be of assistance in providing further information, please do not hesitate to contact me through my office.

STATEMENT OF THE AMERICAN ACADEMY OF CHILD PSYCHIATRY

The American Academy of Child Psychiatry is a national, professional association of over 2700 physicians who have completed a general psychiatry residency and two years additional fellowship training in child psychiatry. Child psychiatrists are highly trained professionals, educated in medicine with special focus and training in the psychiatric disturbances of childhood and adolescence. Child psychiatry is the medical discipline concerned with the development of children and adolescents, their families, their environments and their disturbances in cognitive, interpersonal, emotional and social development, their maladaptive behaviors and their functional deficiencies.

In the United States, an estimated 7 to 9 million children have emotional disorders that need psychiatric treatment, yet fewer than 10 percent of them are served by any of the mental health practitioners. In 1976, 655,000 children and adolescents under 18 received some kind of care through traditional mental health agencies. Of those children who were admitted for care, 87 percent were admitted for outpatient care, and 12 percent for inpatient care.

There are approximately 3 million severely emotionally disturbed children and adolescents. Two-thirds of these children do not receive any help. The scarcity of child psychiatrists contributes to this underserving of disturbed children. Three thousand child psychiatrists practice throughout the United States, with some states listing only one or two for their entire population. This is especially true of rural populations. (See attached summary of geographical distribution of Academy membership in 1982)

Mental illness in children and adolescents includes such serious disorders as anorexia nervosa, childhood psychosis, childhood schizophrenia, behavior disorders, autism, and depression. There is an increasing prevalence of alcoholism, continued drug abuse, and increasing suicide and violence in adolescents. The specific number of severely and/or chronically mentally ill children is difficult to estimate because of the complex determining factors, but even if only one-tenth of all children with psychiatric disturbances were so classified under the conservative estimate of a 7 million total, 700,000 children would have long-term, possibly life-threatening illnesses. If all 3,000 child psychiatrists now practicing in the United States devoted themselves exclusively to this most needy population, each would have 233 such children to care for.

To alleviate this acute shortage of child psychiatrists and provide better services to emotionally disturbed children and adolescents, the American Academy of Child Psychiatry recommends increased appropriations for the following programs:

1. The Clinical Training Program under the National Institute of Mental Health
2. A Children's Initiative modeled after the Community Support Program under the National Institute of Mental Health
3. The Mental Health Research Program under the National Institute of Mental Health

The Administration's 1984 budget proposal which eliminates all clinical training funds is a serious mistake. The fifteen percent increase in mental health research funds is needed and appreciated, but with only 3,000 child psychiatrists in the United States, to remove financial assistance for Fellows creates an additional barrier to the two year training program and accepts the consequence that hundreds of thousands of mentally ill children will never be treated.

The Graduate Medical Education National Advisory Committee (GMENAC) in 1980 projected a need for 9,000 child psychiatrists by 1990 in order to meet the needs of children, as indicated by an 8.6 prevalence rate in the population. GMENAC identified child psychiatry with the greatest need to expand of all medical specialities, yet clinical training funds have been reduced or slated for elimination in each of the last three fiscal years.

In FY'83, Congress appropriated $21.5 million for clinical training, a fifty percent reduction from FY'82, and down from an appropriation of $71.663 in FY'80. One of the areas targeted to receive clinical training funds in the FY'83 budget was child psychiatry, and the National Institute of Mental Health representative reported at the most recent meeting of the National Consortium for Child Mental Health Services that there had been a tremendous response to this Congressional directive. The number of child psychiatry trainees has dropped from 564 in 1977 to 499 in 1981, with a low of 426 in 1980, according to the American Medical Association. Without clinical training support, the number of psychiatric residents able to commit an additional two years and corresponding expense to their ten year training would drop rapidly.

In a few weeks, the American Academy of Child Psychiatry will publish a three year study examining the status of and future plans for child psychiatry. The study, _Child Psychiatry: A Plan for the Coming Decades_, examines six areas: academic child psychiatry; clinical training and psychopathology; education and mental health services; health and mental health services; children, families and the law; and prevention. According to the report, "There are now over 100 divisions of child and adolescent psychiatry as parts of departments of psychiatry in U.S. medical schools." Those departments of psychiatry, along with various psychiatric hospital units, provide 130 training programs in child psychiatry that are accredited by the Accreditation Council for Graduate Medical Education. The programs are the product of years of planning, resource development, and individual and department efforts to attract faculty and students. The loss of any federal support could mean loss of the momentum gained in the last decade. Rather than a growing speciality, child psychiatry could become a static or declining profession while the number of psychiatrically disturbed children increases.

The President of the American Academy of Child Psychiatry, E. James Anthony, M.D., Director of the Eliot Division of Child Psychiatry at Washington University in St. Louis, writes that the federal support for training programs, "...has revolutionized the care of emotionally disturbed children in this city, and has had appreciable impact on child services throughout the state." He continues:

> For a training program to exist, funds have to be provided not only for trainees, but also for trainers who then give of their time to ensure continuity of clinical expertise in the area and, therefore, continuity of care for the children. Training is, therefore, a function that affects not only a current generation of needy and disturbed children...but provides for the future.

The training programs provide cost savings to communities wherever they are located. Emergency room evaluations, juvenile court assistance, school system support, and legal evaluations in areas such as child custody are all part of clinical training that extends directly into the community. Kenneth Robson, M.D., Director of Training at the Tufts University School of Medicine, New England Medical Center Hospital, Boston, estimates that residents-in-training provide standard and emergency services on a 24 hour basis that would cost the state three to five times as much elsewhere. Eliminating all federal support for cost-saving training programs would be counterproductive for the economy and for the treatment of psychiatrically disturbed children and adolescents.

The American Academy of Child Psychiatry supports the appropriation of $25 million for clinical training in 1984. This amount will allow the 1983 training programs to continue and will allow $3 to $5 million for new child psychiatry trainee applications.

To assist states and communities to plan and direct services for severely emotionally disturbed children and adolescents, the Academy recommends appropriating funds for a children's support program modeled after the Community Support Program. Children and adolescents with severe emotional problems need longer inpatient hospitalization than adults, but when state services supporting child and adolescent mental health are fragmented, alternatives to hospitalization are reduced. By providing core funding to states, a network of assistance could be set up among all programs dealing with children and adolescents, such as drug and alcohol abuse, juvenile justice, nutrition, child welfare and education.

Without assistance, it is difficult to provide multiple services to individual children and adolescents when the services are part of diverse government agencies. According to the recently published book, Unclaimed Children: The Failure of Public Responsibility to Children and Adolescents in Need of Mental Health Services,

> Only seven states have departments of mental health that have taken even limited, explicit steps to create systems of care for children and adolescents. In these states there have been sustained efforts to increase the range of mental health services available, reduce the fragmentation of services, and counter the rigidity often built into mental health funds.

By initiating a children's support program, Congress would be assisting the remaining states to create systems of care appropriate to their separate needs. If the children's initiative receives an appropriation of $5 million in 1984, 25 new starts, at $200,000 per state could be funded.

The American Academy of Child Psychiatry supports the appropriation of $5 million for a children's initiative modeled after the Community Support Program within the National Institute of Mental Health.

All of the mental health appropriations requests supported by the Academy would help provide quality care for thousands of children and adolescents. The total request for $30 million for both clinical training funds and a children's support program should result in long-term savings. With clinical training programs allowed to continue without interruption, a medical speciality that is in great need would be supported, providing valuable services to emotionally ill children and to the states and communities serviced by the trainees.

Summary: The American Academy of Child Psychiatry supports the currently proposed 15 percent increase in the National Institute of Mental Health's mental health research budget, an increase of $13.8 million for the 1983 level of $172.1 million. The Academy further requests and recommends that $25 million be appropriated to the NIMH budget for clinical training, and that $5 million be appropriated for the initiation of a state support system for severely emotionally disturbed children and adolescents.

MEMBERS, AMERICAN ACADEMY OF CHILD PSYCHIATRY

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SUBCOMMITTEE RECESS

Mr. SANCHEZ. Sure.

Senator PROXMIRE. The subcommittee will stand in recess until Monday morning, May 2, when we will convene in this room to continue public witness testimony on the fiscal year 1984 budgets for the Department of Health and Human Services and the Department of Education.

[Whereupon, at 11:55 a.m., Friday, April 29, the subcommittee was recessed, to reconvene on Monday, May 2.]

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